

Research paper

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Managing people with long-term conditions



An Inquiry into the Quality of General Practice in England

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This paper was commissioned by The King's Fund to inform the Inquiry panel.

The views expressed are those of the authors and not of the panel.

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Executive summary

Better management of people with long-term conditions has been a key priority of the NHS since the early 1990s. At that time it was recognised that if people with long-term conditions were managed effectively in the community, they should remain relatively stable and enjoy a quality of life free from frequent crises or observed increases in hospital visits. However, relatively little information exists on what constitutes best practice in terms of the role that general practice should play in this care alongside other primary, community and social care providers.

This report forms part of the inquiry into the quality of general practice in England commissioned by The King's Fund. Its core aims are to:

- establish what constitutes best practice in the management of long-term conditions (LTC management)
- describe the role that GPs and the wider general practice team should play in delivering high-quality care to those people with long-term chronic illnesses
- make an assessment of current care quality
- establish whether measures of quality in LTC management could be developed to support quality improvements in general practice, and what these might be.

The research undertook a literature review of the evidence and best-practice guidance supplemented with face-to-face interviews with selected expert informants. The research focused on six key areas:

- arthritis
- dementia
- depression
- diabetes
- people with multiple long-term conditions
- managing long-term conditions across a population.

Arthritis

The current state of care quality to people with both osteoarthritis and rheumatoid arthritis is difficult to determine given the lack of objective quality measures. However, the evidence suggests that care quality is currently highly variable and sub-optimal and could be significantly improved.

A better understanding of the condition among primary care professionals is required, and a more proactive approach to care management is needed. General practice has a core role to play, but delivering high-quality care to people with arthritis should be shared across care settings and multi-professional teams.

Dementia

Research suggests that early diagnosis and intervention is important in increasing the quality of life and life expectancy of people with dementia, and that general practice plays a pivotal role in this. However, while the vast majority of first diagnoses for suspected dementia occur in general practice, this often occurs late in the illness or at a time of crisis, when the opportunities for the management of the condition to maximise quality of life have passed.

There is evidence to suggest that many GPs are either unable or unwilling to recognise dementia symptoms, for a range of reasons, including:

- an inability to differentiate symptoms that may be attributed to the natural signs of ageing and/or could be confused with other disorders
- the lack of specialist services to which patients may be referred
- the lack of training and/or time to make an adequate diagnosis
- the judgement that such individuals might cope better and feel less distressed if a formal diagnosis were avoided.

There was also evidence of a lack of ownership of dementia care responsibility within general practice, and a lack of necessary partnership working and/or care continuity. However, examples do exist of high-quality care – for example, where general practice has developed ‘in-reach’ services into care homes, or has used multi-disciplinary care and assessment processes.

Currently, there is no widespread use of approaches to measure the quality of dementia care in general practice, although audit criteria that support high-quality care have been developed.

Depression

For people who experience depression over extended periods of time, high-quality care involves being supported by a planned system of collaborative care that involves case management, systematic follow-up and improved integration of primary and secondary care. High-quality care also requires sensitivity towards a patient’s perception of the cause and nature of the problem. The evidence suggests the need for a strengths-based approach that provides treatment while also seeking to aid recovery.

There is a lack of clarity among GPs about what their role should be in the care for people with depression. Our research suggests that GPs possess many of the right skills, but some lack the confidence, support or time to use them. Overall, there is considerable potential to improve the quality of care to people with mild-to-moderate depression in general practice, but there is a need for increased clinical education and training, alongside work to build collaborative care models with specialists and to tackle social attitudes and stigma.

Diabetes

General practice plays a pivotal role in the management of diabetes, and has made a significant contribution to its effective management. Many aspects of diabetes management have improved markedly in recent years, through

better recording and ongoing management (incentivised through the Quality and Outcomes Framework). However, the evidence suggests that there still remains a high degree of variability in performance. For example, only 51 per cent of people with type 2 diabetes, and 32 per cent of people with type 1 diabetes, currently receive all the care processes set out in best-practice guidance from the National Institute for Health and Clinical Excellence (NICE). Key areas for improvement include the initiation and implementation of care planning and the need to share information with patients and among care providers.

People with multiple long-term conditions

The impact of multi-morbidity is profound. People with several long-term conditions have markedly poorer quality of life, poorer clinical outcomes and longer hospital stays, and are the most costly group of patients that the NHS has to look after. There is little evidence suggesting what high-quality care looks like for people with multiple long-term conditions (and hence few quality measures that could be applied). However, what evidence does exist suggests that people with multiple long-term conditions tend to get poorer treatment than others.

The challenges posed by multi-morbidity underline the importance of general practice, but also the need for it to work more collaboratively with other care providers – and vice versa. Problems in the care of people with multiple needs appear to be system-wide rather than specific to general practice. This suggests a need for a collaborative care model comprising multi-disciplinary case management, systematic follow-up, and working that is better integrated – for example between mental and physical health professionals. While GPs or other professionals in general practice might not necessarily take the lead role, they need to work closely with whoever does provide the case management, as well as maintaining clinical responsibility and remaining a locus of care continuity for the patient.

Population management

‘Population management’ refers to the strategic activity of proactively identifying individuals who are at risk of deterioration, with the intention of then developing interventions to help slow that deterioration and avoid the need for institutional care. The use of such approaches to manage long-term conditions across a population has advanced in recent years, with mixed results. General practice appears to have taken a peripheral, rather than central, role.

Where interventions are appropriately targeted, there is great potential in population management for improving care quality for patients with long-term care needs. The involvement of general practice is important to the development of the service – particularly in terms of sharing the data and information they have on patients. The high-quality general practice of the future will need to embrace this contribution to managing populations and so seek to provide more proactive and cost-effective care.

Conclusions

There is a significant amount of guidance and expert agreement on what constitutes high-quality care for people with long-term conditions, but relatively little agreement on the role that general practice should play in partnership with other care providers to deliver it.

Apart from certain indicators developed through the Quality and Outcomes Framework, there is otherwise little data and information to judge current care quality. What evidence does exist suggests that significant improvements have been made in some areas – particularly for diseases such as diabetes, heart failure and chronic obstructive pulmonary disease – but less progress has been made for depression, dementia and arthritis, and these require a more collaborative care model for a higher quality of care to be achieved.

In the future, general practice should play a pivotal role in the delivery of high-quality care to people with long-term conditions as part of a shared care model in which responsibility is distributed across different teams and settings. Currently, quality of care remains variable. This might be significantly improved if a more proactive approach to multi-disciplinary care management were adopted. Measures of quality linked to incentives should be developed to help support general practice to play its part in improving the quality and cost-effectiveness of care to people living with long-term conditions.

1 Introduction

As part of the inquiry into the quality of general practice in England commissioned by The King's Fund, this research report examines the quality of the management of people with long-term conditions (LTCs) and long-term mental health problems.

The core aims of this report are:

- to establish what constitutes best practice in the management of long-term conditions
- to describe the potential roles that GPs and the wider general practice team should play in the delivery of high-quality management of long-term conditions
- to establish whether and what measures of quality in the management of long-term conditions have and could be developed to support quality improvement in general practice.

This report provides a current assessment of what is known about the current quality of long-term conditions management in general practice, including how quality varies from practice to practice. It also reviews the measures (if any) that are used to assess or hold GP practices to account for such quality, provides one or two practical examples of best practice (where these exist), and provides a commentary on the challenges faced by general practice in meeting the quality agenda for long-term conditions management. Finally, the report makes some recommendations on the potential impact for stimulating significant quality improvements in general practice in the management of people with LTCs.

Given that high-quality approaches to LTC management are likely to vary from condition to condition, the research has sought to focus on five key areas:

- arthritis
- dementia
- depression
- diabetes
- people with multiple co-morbidity.

In addition, the research considers the role of general practice in the management of long-term conditions within local populations, since proactive case finding appears important in identifying such individuals who are at risk of hospitalisation and/or home care support.

The choice of the four specific conditions was influenced by the fact that each has been subject to major guidance related to the quality of care in recent years. Taken together, the report attempts to make some generic comments on the quality of management of long-term conditions in general practice, and on how this may be measured and improved in the future.

Report structure

Following a short description of the methodology employed in this research (Section 2), the report begins with a brief overview of recent government policy to show how the proactive management of people with long-term conditions has become central to the reform agenda (Section 3). It then examines in detail each of the four condition-specific areas (sections 4–7) as well as co-morbidity (Section 8), using a common template as follows:

- Background
- What does high-quality care look like?
- What is the role of general practice?
- The current quality of care in general practice
- Measuring quality
- The potential impact of quality improvement.

Section 9 examines the role that general practice should play in the management of LTCs across a population.

Section 10 is a unifying chapter that provides a summary of the key findings and develops an understanding of the generic roles that general practice should play in the management of people with long-term conditions. It also seeks to judge the importance of improving quality, and identifies key measures that may be used for this purpose. The section concludes with a commentary on the specific challenges faced by general practice in delivering high-quality care for people with LTCs.

Methods

The research was undertaken from April to December 2009, and consisted of two key phases of work as follows:

Phase 1: Literature review

The literature review phase of the work included a systematic review of all English policy documentation and published guidance related to the management of people with long-term conditions, with a specific focus on the tracer conditions. In addition, we undertook a non-systematic review of the national and international literature on models of LTC and disease management, to examine the evidence for best practice and the suggested roles that general practice should play.

The research team used PubMed, ASSIA and HMIC bibliographic databases to search for articles on the management of long-term conditions in primary care. The number of articles resulting was further refined for relevance, to choose those that looked specifically at the role of GPs and general practice in LTC management for the conditions selected in the research. An example of the study terms is provided in Appendix 1.

Phase 2: Qualitative research

To supplement the findings from the literature, we carried out face-to-face and/or telephone interviews with a range of key informants, using a

purposeful selection of between 8 and 12 individuals per LTC. We piloted the interview protocol with half a dozen respondents before refining it and creating a general interview template. We then adapted the template for use by LTC and by type of respondent. (For an example of the interview protocol used, see Appendix 2).

Each interview also contained generic questions about the management of people with co-morbidity. Expert informants typically included policy-makers, GPs with a special interest (GPSIs), community nurses, secondary care clinicians, commissioners, lead academics, and representatives from patient groups and/or the third sector. For a list of the numbers and types of expert informants interviewed in the research, see Appendix 3.

The sub-study examining the management of LTC populations took a slightly different methodology, by undertaking a number of field visits to specific case-study sites that had been proactive in risk stratification and case finding. The methodology for this part of the study is explained in Section 9.

2 Policy review

In England, integrating care for the management of people with a long-term condition (LTC), including the ability to promote and support self-care, has become a core strategy for its National Health Service (NHS). For example, the previous government set a central commitment to provide the opportunity for all 15.4 million people in England who have a LTC to receive an integrated and personalised care plan by 2010 (Department of Health 2006b).

Within this main policy lie a number of sub-policies, including:

- the active promotion of self-care strategies to enable people with LTCs to live independently in the home environment (the *Your Health, Your Way* initiative – Department of Health 2009a)
- the piloting of personal health budgets to enable LTC patients and carers to tailor their care packages (Department of Health 2009b)
- investment in population-oriented health management through the use of predictive modelling techniques that enable at-risk individuals and populations to be targeted with appropriate interventions (Department of Health 2007a)
- a movement towards new integrated care organisations, which potentially provide an in-house set of comprehensive health and social care services to registered patients, as well as an advocacy role in brokering the provision of care outwith these organisations (Department of Health 2009c).

The focus on LTC management derives from a policy environment in the 1990s that revealed that a growing proportion of inpatient activity was being fuelled by people with long-term conditions such as asthma, diabetes, and sickle cell anaemia (Department of Health 2004a). It was shown that, if managed effectively (for example, through proactive case finding), activity could be relatively stable and should not result in frequent crisis and observed increases in inpatient stays (Billings *et al* 1993, 2006).

As a result of these observations, it became apparent that a fundamental shift was required in the way care needed to be delivered – from the episodic treatment of illness in institutions to the proactive management of patients in the community. This finding was in line with international evidence showing how the long-term economic burden in health and social care was directly related to people living longer with increasingly complex conditions (see Comas-Herrera and Wittenberg 2003).

LTC management emerged as a key strand of health policy in the late 1990s, with the publication of a number of National Service Frameworks (NSFs) for mental health, cancer, coronary heart disease (CHD) and diabetes. Other NSFs subsequently emerged, including a specific NSF for long-term conditions that was published in 2005 and one for COPD in 2008. These NSFs set out to establish national standards and to identify key interventions for particular care groups or diseases, with the NSF for long-term conditions being the exception to such single-disease specific frameworks.

To facilitate the implementation of standards of LTC management in general practice, the Quality and Outcomes Framework (QOF) (which was adopted from 2004 onwards) placed a particular focus on paying general practice for the achievement of evidence-based performance targets in the identification and management of people with LTCs registered in general practice. Practices are awarded points according to the number of indicators they meet, and they receive funding accordingly.

The QOF was designed to make the monitoring of patients with long-term conditions more proactive. The 18 clinical areas incentivised through QOF include aspects of care to people with dementia, depression, and diabetes that will be reviewed in this study – but not for arthritis or directly for people with multiple co-morbidities. The overall impact of the QOF is contested, but by its very presence shows the importance attached to the role of general practice in managing people with long-term chronic care needs.

In recent years, the application of LTC management into practice has been further prioritised by a number of key policies. In 2004, the government published the *NHS Improvement Plan*, which promised higher-quality care for people with long-term conditions. The document established a new role – the community matron – and pledged to roll out the Expert Patients Programme, in which patients receive intensive education to become experts in their own condition (Department of Health 2004a).

More recent policies have reiterated the importance of LTC management – for example, as set out in the White Paper *Our Health, Our Care, Our Say* (Department of Health 2006a), the *NHS Next Stage Review* (Darzi 2008) and world class commissioning – an approach to systematically improving and making more influential the planning, procurement and performance management of the NHS as a key lever in promoting system redesign and improving health and well-being (Department of Health 2007b). An implicit agenda in these policies has been to better co-ordinate care planning and delivery between health and social care, as well as to focus on upstream interventions that promote health and well-being and minimise illness.

The election of the coalition government in 2010 has since led to a major reform programme of the NHS, though the focus on LTC management looks set to remain a key focus of activity given the need to reduce unscheduled hospital admissions (Department of Health 2010). In particular, the policy has highlighted:

- the need to better involve patients in decisions about their own health to facilitate self-care
- the importance of personalised care planning
- the need to reduce emergency re-admissions to hospitals for those people that could be managed in the community.

Delivering higher-quality care for people with long-term conditions

At present, it is widely recognised that the delivery of high-quality LTC management is not widespread and requires standardisation across the country. Key issues include:

- removing barriers to accessing LTC management

- developing the levers and incentives to enable professionals to deliver it
- supporting the workforce to adjust to a new way of working, including a focus on governance, professional practice and cultural relationships.

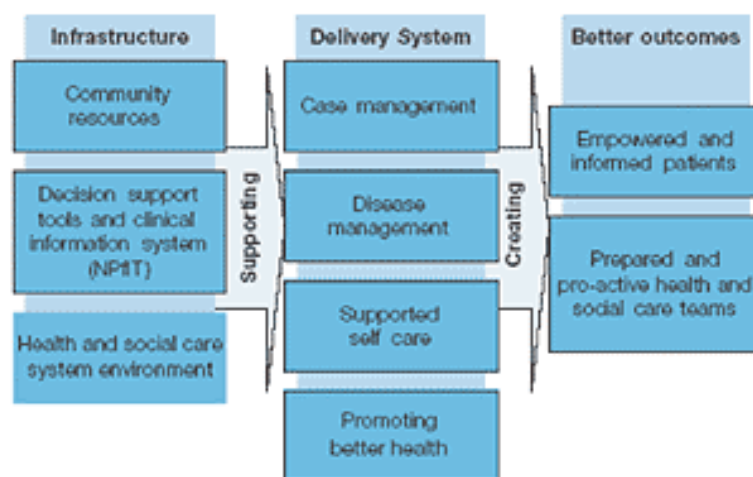
Moreover, while LTC management has become a key priority, relatively little information exists on what constitutes best practice – specifically on the roles that general practice and other primary, community and social care agencies should play within this.

In 2004, at the same time that the QOF was being introduced, an English 'model' of LTC management was set out (Department of Health 2004b). Derived from a number of similar models developed in the United States (such as Wagner's Chronic Care Model and Kaiser Permanente's Population Risk Pyramid), the model was based on three key approaches:

- supported self-care for the majority of those living with – or at high risk of – long-term conditions
- disease management for people with a complex single or multiple conditions who would need to be managed proactively by responsive specialist services
- case management for the small minority of patients with highly complex and multiple conditions requiring high-intensity professional support.

The model is illustrated in Figure 1.

Figure 1 The NHS and social care long-term conditions model



Source: Department of Health (2005a, p 9)

Soon after the publication of the LTC model of care, an NSF for LTCs emerged (Department of Health 2005b). This NSF set out 11 quality requirements for LTC care that should be applied to everyone with one or more LTCs (see Box on p 15). At the heart of the NSF was the need to integrate services to promote independence and empowerment, including working across professional boundaries:

These QRs [quality requirements] are designed to put the individual at the heart of care and to provide a service that is efficient, supportive and appropriate at every stage from diagnosis to end of life. The emphasis throughout this NSF is on supporting people to live with long-term conditions, improving their quality of life and providing services to support independent living... implementing this NSF by 2015 will improve services significantly.

(Department of Health 2005b, p 5)

The 11 quality requirements of the Department of Health's long-term conditions model

1. A person-centred service
2. Early recognition, prompt diagnosis and treatment
3. Emergency and acute management
4. Early and specialist rehabilitation
5. Community rehabilitation and support
6. Vocational rehabilitation
7. Providing equipment and accommodation
8. Providing personal care and support
9. Palliative care
10. Supporting family and carers
11. Caring for people with neurological conditions during admission to hospital or other health and social care settings

Source: Department of Health (2005, pp 4–5)

To support the intensive case management for high-risk individuals with multiple LTCs, the Department of Health invested from 2004 onwards in the creation of a new nurse profession – the community matron (Department of Health 2004a). Community matrons seek to identify patients who meet criteria denoting that they are, or will be, high-intensity users of health care, and provide them with high-intensity help, to ensure that their multiple health and social care needs are met and so enable them to remain at home. The case-management work of community matrons has been central to the government's approach for the management of people with long-term conditions, although the evidence suggests that the cost-effectiveness of the interventions they provide is currently variable, as is their level of engagement with general practice (see Section 9).

The need to better manage patients with long-term conditions outside hospital is now widely accepted, and is embedded in recent policy documents. However, the management of people with long-term conditions is set to remain one of the most pressing challenges to the NHS – not least because of the cold financial climate at the time this report was written. This paper seeks to establish the role that general practice should take to meet this challenge, in order to ensure that patients with LTCs receive high-quality and cost-effective care.

3 Arthritis

Arthritis is the umbrella term used to describe the condition resulting from the inflammation of the joints and bones. There are numerous types of arthritis. These can be categorised as either inflammatory arthritis (IA), non-inflammatory arthritis, or connective tissue disease. It is estimated that one in five people in the United Kingdom is affected by arthritis (Arthritis Care 2007). This section focuses on the two main types of arthritis: osteoarthritis (OA) and rheumatoid arthritis (RA).

Osteoarthritis

OA is the most common form of arthritis. It is characterised by the damage or failure of joints when the connective tissue or cartilage degenerates. This can cause the bones to rub painfully against each other, the growth of new bones in affected joints, or the joints to become misaligned. This process results in stiffness and chronic pain, and thus OA is associated with limitations in carrying out daily activities than other diseases among older people (Jagger *et al* 2006).

OA can have a considerable physical, social, psychological and economic impact on people's quality of life (Breedveld 2004; Gupta *et al* 2005), although research indicates some reluctance among people to report the full extent of the pain they experience and therefore a delay in diagnosis (McHugh *et al* 2007).

The Arthritis Research Campaign (ARC) has estimated that 4.4 million people in the United Kingdom have x-ray evidence of moderate-to-severe OA of the hands, 550,000 of the knees, and 210,000 of the hips (ARC 2002). More than 1 million adults with OA consult their GP at least once a year in the United Kingdom (Arthritis Research UK 2008). Women over 50 years of age are also more likely than men to have OA in their hands, feet and knees (Jagger *et al* 2006). Although some types of OA are hereditary, there are four main risk factors for developing the condition:

- congenital abnormalities
- injury or surgery
- being overweight or obese
- occupation.

Rheumatoid arthritis

Rheumatoid arthritis (RA) affects the body's immune system by attacking the joints and causes them to become inflamed (Arthritis Research UK 2008). RA can limit motion and lead to the degeneration of bone and cartilage. It is unclear what causes the body's immune system to attack joints. However, it has been found that RA can cluster in families (ARC 2002) and could therefore be genetic. Other risk factors are potentially involved too, such as the environment, infection or trauma (ARC 2002; ARMA 2004a).

As the Arthritis and Musculoskeletal Alliance (ARMA) has highlighted, some people may experience a remission in RA (ARMA 2004b). However, for

others the condition can damage joints and cause disabling pain, 'flare-ups', stiffness and reduced function in joints. All of these contribute to a substantial impact on people's quality of life. However, evidence suggests people with RA can be reluctant to seek help from their GP, as they attribute pain to other causes or feel pessimistic about receiving help from health care professionals (Sheppard *et al* 2008). Initial reluctance to consult GPs was found to be the principal reason for the delay between onset of RA symptoms and rheumatologist assessment (Kumar *et al* 2007).

The National Audit Office (NAO) estimated that 580,000 adults in England have RA, and an estimated 26,000 new cases are diagnosed annually. Forty-five per cent of people with RA are of working age, and over 60 per cent have lived with the condition for more than 20 years (NAO 2009). Women are almost three times more likely than men to be affected by RA (arc 2002). RA is more prevalent among people aged over 65 years of age, but it is most likely to develop between the ages of 30 and 50.

Those who are affected by RA at working age can experience difficulty in staying in employment. In a longitudinal study of 353 people, after five years approximately 22 per cent had stopped work due to RA (Young *et al* 2002). In 2007/8 the estimated cost of incapacity benefit for RA was £122 million, and the estimated annual cost of RA to the NHS in England is £557 million, of which £171 million can be attributed to GP activity, such as blood tests and visits (NAO 2009).

Musculoskeletal conditions in general are the most common reason for recurring GP visits, and make up 30 per cent of primary care consultations (Department of Health 2006c). OA and RA are chronic and debilitating conditions, but in both cases early identification and intervention and ongoing monitoring and support can minimise the damage.

What does high-quality care look like?

The *Musculoskeletal Services Framework* (Department of Health 2006c) outlines how GPs and others are responsible for the 'active management' of arthritis through:

- facilitating self-management
- giving the patient information
- interfacing with other primary care services.

It also suggests that general practice and others should support people to return to work. Other key guidelines on the management and standards of care for OA and RA that illustrate what high-quality care should look like are outlined below.

High-quality care for OA

There are two main guidelines for the management of OA, from the National Institute for Health and Clinical Excellence (NICE) and the Arthritis and Musculoskeletal Alliance (ARMA):

- *The Care and Management of Osteoarthritis in Adults: Clinical guideline 59* (NICE 2008b)
- *Standards of Care: Osteoarthritis* (ARMA 2004b).

The NICE (2008a) guidelines establish a number of key priorities for the management of OA, and set out the need for:

- an holistic assessment of the person (focusing on function, quality of life, occupation, mood, relationships and leisure activities)
- provision of education and advice – for example, to encourage patients to self-manage by strengthening muscle and fitness through exercise
- provision of analgesia
- timely referral for joint-replacement surgery where applicable.

Information and advice on self-management also feature in the ARMA (2004b) guidelines, which recommend ensuring prompt access to services to enable early diagnosis and treatment, as well as ongoing support.

The experts interviewed as part of this study commonly reported that the NICE and ARMA guidance was representative of best practice. However, they felt that a broader awareness of arthritis would underpin a GP's willingness to accept patients' musculoskeletal complaints as more than 'just aches and pains' and their readiness to help. They commonly reported that diagnosis needed to be followed up by a patient-centred care plan that emphasised weight loss and physical exercise. The care plan should enable the patient to be referred to professionals within a multi-disciplinary team, such as physiotherapists, occupational therapists or specialists if necessary.

High-quality care for RA

A number of guidelines applicable to RA have been produced, including:

- *The Management of Rheumatoid Arthritis in Adults. Clinical guideline 79* (NICE 2009c)
- *Standards of Care. Inflammatory Arthritis* (ARMA 2004a)
- *18 week Commissioning Pathway Inflammatory Arthritis (Joint Pain)* (Rheumatology Futures Group 2009).

In order to prevent the progression of RA and so reduce the likelihood of developing severe disability, all the guidance recommends aggressive treatment (involving disease-modifying anti-rheumatic drugs), commencing ideally within three months of symptom onset (Emery *et al* 2002; Nell *et al* 2004; Luqmani *et al* 2006). This, of course, depends on early and appropriate diagnosis and referral from general practice. According to the NICE guidance (2009 RA), referral for specialist opinion should be made for any person with suspected persistent synovitis of undetermined cause. This should be done urgently if:

- the small joints in the hands and feet are affected
- more than one joint is affected
- there has been a delay of more than three months between onset of symptoms and seeking help.

In addition to the RA guidance, experts interviewed suggested that referral to specialists should be made if any of the three symptoms proposed by Emery *et al* (2002) are present:

- three or more swollen joints

- experiencing pain on squeezing the metatarsophalangeal or metacarpophalangeal joints
- experiencing 30 minutes or more of morning stiffness.

There was unanimous agreement among the experts interviewed that high-quality care for RA requires the early recognition of symptoms and a prompt referral to a specialist for diagnosis. Those we interviewed accepted as important the current recommendation in NICE guidance for treatment to commence promptly following diagnosis.

For example, NICE (2009c) recommends that a combination of disease-modifying anti-rheumatic drugs (DMARDs) be offered as soon as possible for newly diagnosed RA. Treatment should be monitored rigorously and regularly in outpatient appointments, reflecting the 'tight control' model used for diabetes management (Emery 2006). Once RA control is achieved, DMARD doses should be reduced cautiously (NICE 2009d). This requires regular check-ups to monitor the effects of medication on RA as well as any side-effects. Analgesics, NSAIDs and biological drugs can be prescribed in certain circumstances (NICE 2009d).

According to the majority of expert informants that we interviewed, high-quality care in general practice would also involve awareness of the potential for patients to have or develop other long-term conditions, such as cardiovascular disease or depression. Annual, or more frequent, check-ups in primary or secondary care should consider the possibility of the patient having co-morbidities, and should include checks on blood pressure and weight (for example). NICE guidelines for RA also recommend access to a named member of the multidisciplinary team who is responsible for co-ordinating care provided by other health care professionals, such as physiotherapists, occupational therapists and psychologists.

People with RA can experience very painful flare-ups, and the experts we interviewed were in agreement that, in such an event, it was important to have access to the most appropriate type of treatment – ideally within 24 hours. This could be achieved, for example, by speaking to a specialist nurse via a telephone helpline. The specialist nurse could then facilitate an appointment for a joint injection. Prompt access should also be accessible out of hours.

The expert informants also described aspects of high-quality care that applied to arthritis in general, such as the importance of the patient being informed and thus empowered to carry out self-management of their condition – particularly through physical exercise and weight loss. This would be achieved through the provision of well-designed and appropriate information that gives a realistic but positive outline of:

- what the condition is
- what might happen in the future
- what to do when pain is experienced
- services to contact for help and advice.

The experts felt that health care professionals needed to support patients to manage their pain by recognising the psychosocial impact of the condition and discussing their concerns and/or referring them to organisations such as Arthritis Care or NRAS, which provide information and peer support. Patients

have concerns about either remaining in or returning to employment. High-quality care would involve health care professionals discussing such concerns with patients and making referrals to other professionals where possible or signposting to patient groups.

The theme of patient-centred care emerged strongly from interviews with experts. One respondent highlighted that the location of care needed to be physically accessible to people with mobility problems, while another suggested the importance that care professionals were prepared to discuss a patient's general well-being: how they are coping and what their concerns are. This, in turn, would enable the patient to take better control of their condition:

I think at the end of the day it is all around providing holistic care, which puts the patient at the centre of the journey. With arthritis – be it osteo- or rheumatoid or whatever – these are usually long-term, lifelong conditions, and patients have to learn to live with and live around this difficulties and overcome the problems... So you actually plan the care around what the patients perceive to be important and actually allow patients more control over their journey – again, obviously, advised where there is clinical need as to what is safe and appropriate.

GPSI in rheumatoid arthritis

What is the role of general practice?

The majority of people with arthritis symptoms will seek their help in the first instance from a GP (NAO 2009). The literature and the expert interviews showed that the course of treatment very much depends on what GPs do at this initial stage:

General practice is crucial because it's got to recognise what needs referring and what doesn't, at the earliest stage. If you just wait and watch, then that's the worst option – because you've actually allowed chronicity to occur.

Professor in rheumatology

This study – encompassing, as it does, a review of the literature, best-practice guidance and the views of expert informants – suggests that high-quality care in general practice in the management of people with arthritis would need to fulfil the following core aspects of care and management.

- **Early recognition of symptoms and prompt diagnosis** Professionals in the general practice setting (and GPs in particular) must be aware of arthritis and be able to recognise its symptoms. Awareness is particularly important given that some patients do not present musculoskeletal pain as their primary complaint. In cases of RA, prompt and accurate diagnosis – perhaps with support of a specialist or GPSI – is important.
- **Prompt and appropriate referral** In cases of RA, the GP should use the guidelines to make a prompt referral to a specialist, ideally within the first or second consultation. Prompt referral would be enabled by establishing a referral protocol with the local specialist team. This would require both parties to be willing and able to communicate with each other. The expert informants felt that the subsequent diagnosis of RA should be made by a rheumatologist or a GP with special interest,

as they would have the appropriate level of expertise to interpret diagnostic tests. Specialists would also have the expertise to prescribe the course of medication needed to stabilise the patient's RA.

In contrast, in cases of OA GPs are able to make a diagnosis in the majority of cases.

- **In emergency flare-up situations, GPs should facilitate rapid access to treatment** This should take place ideally within 24 hours – for example, by contacting the nurse specialist or rheumatologist.
- **Patient information and supported self-care** Following diagnosis, GPs or practice nurses should provide patients with either verbal or written information about their arthritis. GPs or practice nurses should signpost patients to patient groups and ensure they can access a support network.
- **Patient-centred care plan** Diagnosis should be followed with a care plan, developed in partnership with the patient, to enable them to understand the health-promoting activities they should seek to follow (for example, weight loss or physical exercise). These should enable the patient to understand the next steps in their treatment.
- **Proactive case management** The general practice team should undertake long-term monitoring of patients with arthritis. They should monitor how medication is affecting the condition and the person, whether any co-morbidities are present, and the patient's general well-being. This requires the professional to be empathetic, and to give serious consideration to patients' concerns about employment, child care and relationships.

Some experts felt that GPs had limited time to do this and that the practice nurse might therefore be better placed to assess the psychosocial aspects of care, as well as to provide the motivation and support to make lifestyle changes. If the patient's psychosocial needs cannot be met within the general practice, the nurse or GP should signpost them to other services:

There are core issues for all long-term condition patients that they need right from the beginning. They need proactive, positive support, good messages right at the beginning of their journey. They need the information that's going to empower them. They need reassurance, and they need rapid access when they can't cope. And nurses are brilliant at putting the context of that in a patient-centred approach that looks at the social and psychological needs of that patient.

Rheumatology nurse consultant

- **Ongoing care** GPs can provide ongoing prescriptions for medication if appropriate. In the case of RA, prescriptions should be consistent with what the specialist has prescribed, based on regular monitoring.
- **Multi-disciplinary team-working** GPs or practice nurses should make referrals to a multidisciplinary team (such as physiotherapists, occupational therapists or surgeons) as needed. Within this process, they should discuss choices and support patients in making them.

The current quality of care in general practice

When it comes to the quality of arthritis management, the published evidence suggests that performance within general practice is not always consistent with guidelines – a view generally backed up by the experts we interviewed during the study.

For example, a recent NAO (2009) report found that less than 50 per cent of people with RA are referred by their GP to a specialist within three months, while people with RA visit their GP an average of four times before being referred (Steward and Land 2009). One reason proposed for the delay in diagnosis of long-term musculoskeletal conditions is a lack of knowledge and awareness about these conditions among GPs. This could be exacerbated by the fact that less than half (43 per cent) of PCTs provide education to GPs about inflammatory arthritis (ARMA 2009).

In addition to this apparent lack of knowledge, some experts also suggested there was a lack of interest among GPs in treating arthritis, as it is not currently a long-term condition that attracts incentive payments through the QOF:

In their years of training to be a doctor, GPs get two hours' [training]¹ on musculoskeletal (conditions)... You've got people in society who think arthritis isn't something you should bother about, so they don't go and present... And nothing in the QOF to incentivise them to anything anyway. All these pressures to do nothing. So people get worse, they deteriorate, they give up their job, they get depressed, they become expensive users of health and social care systems – when they could, if caught early, be kept mobile, be kept independent, pay tax through having jobs, not claim disability benefits. So much to be gained from it, and yet there's so little being done about it.

Chief executive, arthritis support organisation

These impressions are supported by a recent study by the think tank RAND (Steel *et al* 2008) that revealed how only 29 per cent of eligible patients for OA treatment by a specialist had been provided with the care they should have received – the lowest figure in comparison to nine other conditions they examined. Research by Broadbent *et al* (2008) that assessed the self-reported quality of care for 320 patients at various general practices showed a low level of satisfaction with the level of information they were provided about their condition (17–30 per cent) and a wide-ranging set of views in terms of quality of treatment (5–90 per cent).

Regarding treatment provision for OA, research carried out before NICE guidelines were introduced shows variation in general practice according to the type of OA treated and the type of treatment. For example, OA in the knee is more common than OA in the hips. However, data suggests that following referrals, hip replacement surgery is more likely to occur than knee replacement surgery (Linsell *et al* 2005). The data also suggests that pharmacological interventions are favoured compared to exercise, weight loss and physiotherapy (Jordan *et al* 2004; Porcheret *et al* 2007).

1 This refers to the NAO (2009) report, which showed 70 per cent of trainee GPs had tutorials on musculoskeletal conditions, receiving an average of two hours teaching on back pain, joint injections and OA.

Regarding information provision for OA, research indicates that GPs are not always providing this adequately, and/or that patients do not recall receiving it (Victor *et al* 2004; McHugh *et al* 2007). Interviews with our expert informants also raised a common concern that patients do not feel they are given enough information about how to manage their condition.

The NAO (2009) study of services for RA looked at care provided to 1,200 individuals. It concluded that the likelihood of RA being diagnosed and treated within the 'window of opportunity' had not increased since 2003, despite the introduction of the 18-week target from referral to treatment. The study also showed that half of those who had experienced a delay in diagnosis attributed this to their GP. Respondents said their GPs had been unable to make a diagnosis based on test results, had made a misdiagnosis, or had taken a long time to make a specialist referral. Specialists would usually repeat the tests, thus leading to more delay and cost.

Interestingly, the majority of GPs in the NAO study said they had either 'very good' or 'some' knowledge of RA (96 per cent), but 74 per cent were 'somewhat confident' in making a diagnosis, compared to 18 per cent who were 'very confident'. This dissonance between GPs' knowledge of RA and their ability to diagnose reflects the literature and expert interview data, which suggests that GPs are not confident that they can manage RA as well as specialists can (see, for example, Memel and Somerset 2003).

Measuring quality

At present, no robust or routinely collected measures are currently in use in general practice to monitor the quality of care for people with arthritis. Arthritis is not a clinical area prioritised through the QOF. However, there have been some quality indicators developed by RAND, NICE and the National Primary Research and Development Centre (NPRDC) regarding OA treatment in primary care (Broadbent *et al* 2008 – see Table 1).

RAND has also developed a set of 27 validated quality measures for treatment of RA that spans physician and rheumatologist care (MacLean *et al* 2004). However, there is no evidence to suggest that such indicators are being collected or used with general practice or any other care provider in the United Kingdom. None of the experts interviewed believed they were aware of any measures currently used to assess the quality of care in general practice for OA or RA.

Two expert informants felt that, despite the availability of best-practice guidelines, without the existence and use of quality measures there was little current incentive to improve quality:

That is the trouble with guidelines. You can have as many guidelines as you like, but... unless practices are measured by the Care Quality Commission, or whoever it is actually going to be measuring that, and equally measuring patient satisfaction, I don't think it is going to make any difference.

Director, musculoskeletal conditions group

I think getting some musculoskeletal measures on QOF would be the single biggest step to improving quality of care. Unfortunately, money talks – and with only a limited amount of time in the day, if it is not part of QOF it is put on the 'to do' list sometime, and never gets done. So certainly

the biggest thing that could help arthritis care is to get musculoskeletal measures on QOF.

GPSI in rheumatoid arthritis

Table 1: Quality indicators for osteoarthritis treatment in primary care

	Quality indicator	Source
Information provision indicators	The percentage of patients with symptomatic OA whose notes contain a record that they have been offered education regarding the natural history, treatment, and self-management of the disease at least once	RAND
	The percentage of patients with OA treated with an NSAID whose notes contain a record that they have been advised of the gastro-intestinal and renal risks associated with this drug	RAND
Regular assessment indicators	The percentage of patients treated for symptomatic OA whose notes contain a record that they have been assessed for functional status in the last year	RAND
	The percentage of patients treated for symptomatic OA whose notes contain a record that they have been assessed for degree of pain in the last year	RAND
	The percentage of patients with OA regularly treated with NSAID whose notes contain a record that they have been asked about gastro-intestinal symptoms within the previous 12 months	RAND
Treatment provision indicators	The percentage of patients in whom oral pharmacological therapy was initiated to treat OA and whose notes contain a record that they were offered paracetamol first (unless contra-indicated)	RAND NPRDC
	The percentage of patients with OA treated with an NSAID whose notes contain a record that ibuprofen (or a cox-2 inhibitor) has been considered for first-line treatment (unless contra-indicated or intolerant)	NICE NPRDC
	The percentage of patients with severe symptomatic OA of the knee or hip that has failed to respond to non-pharmacological and pharmacological therapy and whose notes contain a record that they were offered referral to an orthopaedic surgeon to be evaluated for total joint replacement within 6 months unless surgery is contra-indicated	RAND
	The percentage of patients in whom oral pharmacological therapy was changed from paracetamol to a different oral agent and whose notes contain a record that they were offered a trial of maximum-dose paracetamol	RAND

Source: Adapted from Broadbent *et al* (2008)

The potential impact of quality improvements

The NICE costing report that accompanied the publication of OA treatment guidelines in 2008 showed that full implementation of the guideline was estimated to lead to annual savings of nearly £7.3 million, through reduced GP consultations and hospital admissions (NICE 2008a). Further, evidence suggests that physical exercise and physiotherapy can be cost-effective for knee pain (Segal *et al* 2004; Jessep *et al* 2009). In terms of RA, improved treatment of recent-onset RA should avoid or delay the onset of disability (NICE 2009c). Reduced costs to the NHS can be inferred from the reduced

likelihood of severe disability. It was not possible for NICE to quantify the NHS savings arising from prompt access to specialist care.

According to the NAO (2009), if services to people with arthritis were reconfigured to ensure quicker diagnosis and earlier treatment, the short-term costs to the NHS would increase but there could be productivity gains and better quality of life for patients in the long term. Increasing the number of patients seen within three months of symptom onset to 20 per cent (from the current figure of 10 per cent) could initially increase the cost to the NHS by £11 million over a five-year period, due to expenditure on drugs and the associated monitoring of patients. This could become cost-neutral after approximately nine years, and then there could be productivity gains of around £31 million for the economy due to reduced levels of sick leave and lost employment. Further, quality of life could increase by 4 per cent over the first five years in terms of quality-adjusted life years (QALYs) gained (NAO 2009).

Clearly, the current state of quality of care for people with OA and RA in general practice is problematic to determine, due to the lack of objective measures and indicators available. However, the evidence examined here would suggest that it is currently sub-optimal and highly variable, and could be significantly improved through a better understanding of the condition among primary care professionals and a more proactive approach to care management (which might also prove cost-effective to implement). What is clear is that responsibility for delivering high-quality care to patients with arthritis should be shared across care settings and multi-professional teams, and that general practice has a core role to play as part of that continuum of care.

4 Dementia

Dementia can be described as 'a syndrome which may be caused by a number of illnesses in which there is a progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities' (Department of Health 2009d, p 15).

There are estimated to be approximately 750,000 people living with dementia in the United Kingdom at present, though the number is set to increase to more than 1 million people by 2025 (Alzheimer's Society 2007, 2010). While dementia is predominantly a disorder that affects people in later life (its incidence and prevalence rise exponentially with age), it also affects about 12,000 people under the age of 65 (NAO 2007a). Late-onset dementia – especially Alzheimer's disease – is also more prevalent among women.

It is estimated that 11,000 members of black and minority ethnic background have dementia, with members of BME communities comprising 1.7 per cent of the total population with dementia (Alzheimer's Society 2007). There is a greater likelihood of dementia prevalence in areas where larger proportions of older people live. Overall in the United Kingdom, 10 per cent of deaths among men over 65 years, and 15 per cent of deaths among women in the same age group, are linked to dementia. The majority of dementia-related deaths occur between the ages of 80 and 95 years (Alzheimer's Society 2007).

Dementia is characterised by a decline in a person's memory, reasoning and communication skills and their ability to carry out daily activities. Simultaneously, a person with dementia may also develop behavioural and psychological symptoms, such as depression, psychosis, aggression and 'wandering' (Department of Health 2009d). Dementia is largely an irreversible condition (NICE/SCIE 2006a). There are numerous forms of dementia including:

- Alzheimer's disease caused by clumps of protein (or 'plaques') developing around brain cells (NHS Choices 2010). This accounts for 62 per cent of dementias in England (NAO 2007a)
- vascular dementia caused by restricted blood circulation to part of the brain (NHS Choices website)
- dementia with Lewy bodies caused by protein developing inside nerve cells (NAO 2007a)
- fronto-temporal dementia caused by the shrinking of the frontal and temporal parts of the brain. This occurs mostly among people under 65 years of age, and is much rarer than other types of dementia, affecting 2 per cent of people with dementia in England (NAO 2007a).

The causes of dementia-related illnesses are not well understood, but all result in changes from structural and chemical changes in the brain leading to the death of brain tissue. The progression of the various types of dementia varies. However, in general terms, there are three phases: early, middle and late stage:

- Early-stage dementia can often be misinterpreted as symptomatic of other problems, such as stress or ageing, because it can be indicated by short-term loss, confusion and anxiety.

- In the middle stage, people require more support as they become increasingly forgetful, and they can become distressed or angry.
- In the late stage, symptoms can include:
 - being unable to easily recognise familiar objects, surroundings or people
 - becoming increasingly frail
 - developing a progressive slow or unsteady gait
 - difficulty eating
 - incontinence
 - gradual loss of speech (NAO 2007a).

Understandably, the onset of such symptoms can have a profound impact on the quality of life both for the person with dementia and their relatives and friends, who can also be their caregivers (Alzheimer's Society 2007). People with dementia typically live for between seven and 12 years after diagnosis (Department of Health 2009d p 17).

What does high-quality care look like?

A number of documents have been published recently outlining what high-quality care for people with dementia should include. Examples include:

- guidance published by NICE/SCIE (2006a) emphasising the need for integrated health and social care
- the national dementia strategy (Department of Health 2009d)
- the NICE technology appraisal for various drug therapies for Alzheimer's disease (NICE 2007).

Generally, the experts interviewed as part of this study agreed with the published guidance, and provided more detail on how it should be implemented in the context of general practice.

The national dementia strategy argues that high-quality care can be achieved for dementia sufferers and their carers only if a shift is achieved in the way that society – including health and social care professionals – perceive dementia (Department of Health 2009d). Positive changes in attitudes and beliefs about the disease, and about the needs of people living with it, could encourage people with symptoms to seek help, and could encourage health care professionals to offer help by referring for a diagnosis. Similarly, the NICE/SCIE guidance (2006a) sets out that when a health care professional is approached by an individual (or their carer) with potential symptoms of dementia, he or she should be willing to take appropriate action:

The professional should not dismiss the signs of dementia and should seek to obtain a diagnosis as soon as possible so that treatment can begin. Health care staff should consider referring patients showing signs of mild cognitive impairment for assessment because over 50% of people with such symptoms then go on to develop dementia.

(NICE/SCIE 2006a, p 22)

According to the NICE/SCIE (2006a) guidance, a number of tests or assessment should be carried out to obtain an accurate diagnosis of dementia, including:

- a full medical history
- a medication review
- a clinical cognitive assessment using a standardised instrument such as the Mini Mental State Examination (MMSE) (though this has subsequently been found to be ineffective for diagnosis in certain groups)
- blood tests (to rule out other conditions)
- structural imaging tests.

The guidance argues that there should ideally be a rapid referral to a specialist (such as a geriatrician, neurologist or psychiatrist working in a memory clinic) to carry out these tests and assessments and/or interpret the results to make an informed diagnosis. An early diagnosis can enable health and social care teams, the individual and their carers to maintain the independence of people with dementia for as long as possible (NICE/SCIE 2006a). An accurate diagnosis may require the individual to make a number of visits to the specialist team. Ideally, the diagnosis of dementia should be conveyed to the patient by a specialist (or GPSI) and then communicated to the patient's GP.

When it comes to conveying the diagnosis of dementia to the patient, the evidence shows that some GPs and other health care professionals are reluctant to break this type of 'bad news' to patients. This may be because they are under the impression there is no point in making a diagnosis if there are no treatment options or support services available for the person. Alternatively, it may be because the professional does not wish to distress the patient or the carer by telling them they have a terminal condition. However, the guidance and the data from the expert interviews shows that it is important for the professional to be forthcoming with the diagnosis, and to handle this with due sensitivity. Nonetheless, for certain types of dementia, it is recognised that drug treatments can help slow the progress of the disease (and potentially reduce anxiety) if caught early enough.

Providing that a diagnosis is made and given to the patient early on during their illness, plans can be made for the ongoing care of the individual. The individual should undergo an holistic assessment that considers their medical, psychological and social care needs. The earlier these discussions occur, the earlier the various aspects of care can be arranged and therefore the individual stands a better chance of having a better quality of life:

One of the cornerstones [of dementia care]... is that if you tell people earlier, they can do stuff about it... They need to know what's going on, because one of the things that gets lost in dementia as you become more severely ill is your insight into having dementia. Then, if you want to accurately forward plan, if you want to carry out advanced planning, if you want to say what sort of risk you're willing to put up with before going into a care home, if you want to have those discussions with your family, then if you don't have them when you're first diagnosed, [within] the first couple of years, then you may never be able to have them...

So there's a whole sense of planning for the future... but also there's good definitive evidence to suggest that if you gear up carers and people with dementia at the beginning of their journey, they'll have a better journey with their dementia – so that instead of having a dementia that is blighted by crises... you have one whereby you know where you can go for help.

Professor of mental health and ageing

There are some psychological treatments that can help people to cope with the symptoms of dementia – for example, cognitive stimulation, behavioural therapy, reality orientation therapy and multisensory orientation. Physical exercise can also be beneficial to mood and mental function. Where appropriate, the specialist team should begin pharmacological treatment. Continuing prescription can be provided in primary care as long as there are good lines of communication between the health care teams.

Based on the holistic assessment of needs mentioned above, the individual and a health care professional should make a care plan and appropriate referrals to other services. A care plan could include a set of goals for the patient to manage risk and stay relatively healthy for as long as possible, such as stopping smoking, controlling blood pressure and cholesterol and taking aspirin as prescribed.

As with a number of long-term conditions, access to information and education about self-management is vital. The patient and their carer should be given access, or signposted, to sources of peer support in the community and voluntary sector for more information about dementia and education on coping strategies. Information is important in helping people to live well with dementia for as long as possible in the community (Department of Health 2009d). The individual and their carer should be given high-quality information, and support to understand it, to suit the different stages of the illness:

I think that the third sector has quite a large place to play in terms of early intervention and support... There's no doubt that behavioural and psychological symptoms are a frequent cause of extreme distress to the relatives, which... can sometimes lead on to people getting admitted [to hospital]... If you can have psychosocial intervention and psychological intervention at that stage, it decreases the admissions.

GPSI in dementia care

Once diagnosis has been made and various interventions have been implemented, the patient will need ongoing monitoring by the different teams involved. Further, the individual and their carer should be able to access information and support as and when required. A pilot scheme is currently being implemented for 'dementia advisors', who act as a named contact person for the individual and their carers following discharge from secondary care. Their purpose is to help the individual and their carer to navigate the health and social care system, so they have easy access to care, support and advice.

Individuals with dementia should have access to high-quality care in all locations. That is, the individual should be enabled to live well in their home through the use of assistive technology, telecare and home visits, as appropriate. The individual is also entitled to high-quality, patient-centred physical and social care in care homes and in hospital settings. The focus on

high-quality care tailored to the individual's needs should apply equally when it becomes clear that he or she is entering palliative and end-of-life care.

Alongside the high-quality care described for the individual with dementia, health and social care staff must also consider the needs of the carer. This could begin with a formal assessment of his or her physical and emotional capacity to provide care to the patient with dementia. The health and social care team must always be aware of the health and emotional well-being of the carer throughout the patient's journey – particularly when it is evident that he or she is experiencing difficulty in coping. Carers should have access to information and support when they need it, including periods of respite during which a care assistant can provide cover.

What is the role of general practice?

The vast majority of first diagnoses for suspected dementia occur in general practice. A typical GP practice can expect their list to include between 12 and 20 people with dementia. According to the NAO (2007a), GPs have 'ultimate' responsibility for each patient with dementia, regardless of whether they are living in their own residence or in a care home. The GP is the constant during the patient's journey with dementia. The GP often carries out a co-ordinating and monitoring role, and acts as a gateway to services that provide the necessary and appropriate intervention and support.

From an assessment of the literature, the guidelines and the views of our expert informants, the role of the general practice in providing high-quality care to people with dementia can be outlined as follows.

- **Awareness of risk factors and symptoms** GPs and practice nurses should be aware of the risk factors for dementia and the appropriate action to take – for example, providing advice – and should review those patients with modifiable risk factors such as smoking, obesity or hypertension. They must be aware of various warning signs and recognise that dementia affects a number of people under the age of 65 as well as the elderly. Symptoms should be taken seriously, and should be discussed in further detail with the patient and, if possible and appropriate, a specialist.
- **Proactive case finding** General practices should take a proactive role in screening all patients for suspected dementia, whether or not this is suggested by the patient or their carer.
- **Assessment** Where dementia is suspected, GPs with the appropriate level of training and knowledge could administer blood tests and standardised cognitive assessments to establish a baseline of information. This could then be provided to a specialist team, which may then wish to carry out subsequent tests before making a formal diagnosis. Practice nurses could be trained up to administer cognitive assessments.
- **Prompt and appropriate referral** Whether or not preliminary assessment tests are carried out in general practice, an early referral must be made to specialist units (for example, memory clinics) with the aim of obtaining an early diagnosis. Formal diagnoses of dementia should be made by specialists. The diagnosis should be communicated

to the general practice, and a register of patients with dementia should be kept there.

- **Shared and proactive care** General practices should have shared care arrangements with specialist services to exchange information. GPs and practice nurses then provide continuity of care, through proactive monitoring and managing the progression of the disease. General practice notes should be kept up to date and synthesised with notes from specialist care teams. Since the individual with dementia is likely to be in contact with a number of different health care professionals, social care providers and other support services, it is important for general practice to work in partnership with these colleagues by sharing and seeking information. General practice plays a vital role in ensuring that the individual can be looked after in the community for as long as they wish – for example, by advocating on behalf of the patient and/or supporting care-home staff.
- **Patient and carer information and supported self-care** As the professional responsible for ongoing care, the GP should discuss the diagnosis with the individual and their carer(s) sensitively. He or she should ensure that the individual understands as much as possible about the diagnosis, its implications and how the management of dementia is likely to proceed. It may be appropriate to signpost the individual and/or their carer to a specialist service for further advice and support in coming to terms with the diagnosis. It should be made clear to the individual that they can also contact the general practice for information if they wish to do so, and that their requests will be given due consideration and treated sensitively.
- **Care planning** General practices should ensure that a care plan with the individual and their carer is undertaken and recorded. The care plan must be tailored to the individual, and might include targets for controlling cholesterol and blood pressure and ensuring medication is taken, as prescribed by the specialist or GP. The care plan should also be seen as an ongoing process to take any changes into account.
- **Ongoing care** The general practice team, in partnership with shared care providers, should carry out holistic assessments of individuals with dementia and his/her primary carer. This information should be used to make referrals to members of the multidisciplinary team, such as community matrons, district nurse teams, social services and voluntary and community-sector support organisations where peer support and education can be accessed. Assessments of the individual with dementia and carer should be ongoing in order to pick up on any changes in circumstances, such as depression or fatigue.

A thorough review of dementia patients should be taken every six or 12 months, depending on need and severity. This should cover physical health such as co-morbidities, infections, weight, blood pressure and cholesterol, as well as psychological issues and social care needs. The GP, practice nurse or dementia advisor based in general practice should be proactive in contacting the individual in between reviews to determine whether there have been any developments.

The various aspects of the role played by general practice described here are underpinned by training in dementia care and knowledge of (and availability of) specialist dementia services. All staff working within general practice should have the appropriate training and skills to deliver high-quality care to individuals with dementia. GPs and practice nurses should be aware of the NICE/SCIE guidance and the national dementia strategy, and practice managers and receptionists should be sensitive to the needs of patients or carers when contacting the practice for information and appointments.

All staff within the general practice should know about existing services in the area for diagnosing and managing dementia and providing support to patients and carers. If there is a lack of specialist services in the area to deliver accurate diagnoses, GPs should be proactive in making sure they are commissioned.

The current quality of care in general practice

It is commonly reported that first contact and diagnosis of people with dementia often occur late in the illness and/or in crisis, when opportunities to manage the condition in order to maximise quality of life and prevent harm have passed (NAO 2007a). There are a number of factors contributing to diagnoses being made late. For example, survey data (Alzheimer's Society 2007) shows that:

- people can wait up to three years before reporting symptoms of dementia to their GP
- 70 per cent of carers report being unaware of the symptoms of dementia before diagnosis
- 64 per cent of dementia sufferers are 'in denial', with 58 per cent believing the symptoms 'just a part of ageing'.

Focus-group data shows that individuals can make a number of visits to the general practice before the GP recognises symptoms and makes a referral to a specialist or memory clinic (NAO 2007b). The same analysis showed delays in diagnosis that occurred because GPs did not act on the possibility of dementia being present in people under 65 years of age, or did not listen to carers' concerns due to patient confidentiality.

The NAO analysed 2006 data on expected and recorded prevalence of dementia in the population. This showed only five people per 1,000 aged 65–69 had been diagnosed with dementia, compared to the estimated actual prevalence of 13 per 1,000. In people aged 80 years and over, only 60 people per 1,000 were diagnosed, compared to the estimated actual prevalence of 122 per 1,000 (NAO 2007a).

The level of UK diagnosis and treatment of people with dementia is not only low, but there is significant variation. For example, one study uncovered a 24-fold variation in activity between the highest and lowest activity by PCT (Knapp *et al* 2007). International comparisons have placed the United Kingdom in the bottom third of European performance in terms of diagnosis and treatment, with less than half the activity of France, Sweden, Ireland and Spain (Knapp *et al* 2007). Late diagnosis means that people with dementia and their carers are less able to make informed plans for their future, and do not gain access to the help, support and treatments that can help.

The experts interviewed in this study often discussed the lack of (or late) dementia diagnoses being made in general practice and the possible reasons for this. Their evidence suggests that most GPs are either unable to recognise dementia symptoms and so make referrals for diagnoses, or unwilling to take action when they do recognise symptoms due to the feeling that little can be done to help.

The interviewees felt there was a lack of specialist services to which patients could be referred, reflecting the findings of the NAO (2007a) report, although some welcomed the development of memory clinics if this led to more speedy and reliable access to such support.

Where GPs were unable to recognise symptoms, expert informants often attributed this to natural signs of ageing and/or argued that such symptoms were easily confused due to their association with other disorders. This view is again backed up in the NAO (2007a) report, which found that only 31 per cent of GPs believed they have received sufficient basic and post-qualification training to diagnose and manage people with dementia appropriately – a lower figure than was reported five years previously (Audit Commission 2002). This shows there is a need to raise awareness and training in dementia care in general practice.

Where GPs were unwilling to take action when they suspected dementia, this is because they assume there is no merit in obtaining a formal diagnosis. For example, the incidence of dementia in residential and nursing homes is likely to be high. However, the research evidence suggests that GPs may not seek to make diagnoses among a population in which a diagnosis will not necessarily add anything to the care they are already receiving (Koch and Illiffe 2009). In other cases, the reluctance to take any action could be due to the GP feeling that the diagnosis will be too distressing for patients who may already be frail and vulnerable, or that they may not fully understand. In other cases, the GP might feel the diagnosis will have a negative impact on the therapeutic relationship:

I think there's also a misconception that dementia is an endpoint and that people have no insight once they have it. 'What's the point of the telling someone they'll lose their ability to remember things, to reason, to look after themselves?' and... 'Why tell people about impending doom when, actually, they can just get on with their lives?'. Of course, we know that people with dementia have very good insight for quite a long time into their condition, so that's not actually true at all.

Representative of national dementia charity

Where dementia has been diagnosed, there also appears to be a lack of ownership of dementia care in general practice. For example, a study into the skills and knowledge of GPs in dementia care found that one-third of GPs surveyed believed dementia care to be the remit of a specialist team (Turner *et al* 2004). Another qualitative study indicated that GPs were more resistant than other professionals to shared care due to staffing and time constraints, lack of experience and lack of confidence in making the diagnosis (Illiffe *et al* 2006).

The experts we interviewed as part of the study emphasised the presence of poor continuity of care in general practices and a lack of willingness to take on the role of case management. Consequently, respondents suggested that

'only the minimum was being done' to review dementia patients, in order to meet the 15-month QOF requirements.

The most recent research to highlight these problems was reported through a cohort study that examined the health records of dementia patients in 353 general practices (Rait *et al* 2010). The study concluded that under-recognition of dementia syndromes persists in primary care, and that greater engagement of primary care in earlier and better detection of dementia is needed. In addition, they found that GPs often record the diagnosis of dementia in a non-specific way, not differentiating between Alzheimer's disease and vascular dementia. This is an important distinction that may affect management, including the use of anticholinesterase inhibitors, and should be covered in educational initiatives or through incentives.

The research suggested that further work was needed to explore factors underlying GPs' decision to record a diagnosis of dementia and enter it on a dementia register, as well as to understand why the mortality rates are higher during the first year after formal recording of a diagnosis.

There are several examples in England where general practices have taken the initiative and sought to minimise the number of late dementia diagnoses. The approaches taken include:

- the provision of 'in-reach' into care homes
- work with multi-disciplinary teams to make an initial assessment
- cognitive testing using standardised assessments (Kock and Illiffe, 2009)

The box below provides one such case example – the Gnossal Memory Clinic.

Case study: Gnossal Memory Clinic

With the assistance of the Alzheimer's Society Hearts and Brains Project, one general practice in Staffordshire has implemented a streamlined pathway for the assessment and care of dementia. The pathway essentially provides the assessment function of a memory clinic within primary care, so that patients have relatively faster and easier access to expert assessment (Koch and Illiffe 2009; Greening *et al* 2009).

The aim of the Gnossal Memory Clinic is to facilitate the diagnosis of patients with suspected dementia in association with vascular disease. The centre has focused on people with vascular problems because these risk factors are the same as for Alzheimer's disease. The GP or practice nurse identifies patients who are beginning to experience problems with memory, concentration and other symptoms. Identification occurs either when patients present with concerns about their memory or other factors, or through routine screening of all patients with known potential vascular risk. Information is then captured during this appointment with the GP or nurse and is subsequently added to by a health visitor. The information gathered includes clinical status, previous history, family history, and details of functional and social needs. The health visitor is the link between the patient, the general practice and the memory clinic, and is a constant during the patient's journey.

A consultant in old-age psychiatry has been commissioned to provide one clinical session per month within Gnosall Memory Clinic. The consultant meets the patient and their carer at their home or at the general practice and makes a clinical assessment, using the information already captured by the GP, practice nurse and health visitor, supplementing this with cognitive tests and scans as necessary. The consultant is also available for discussion and advice over the telephone and via email. Those diagnosed are then referred to specialist teams to begin pharmacological or psychosocial therapies, and this information is shared with the general practice so that ongoing monitoring can be carried out there.

Between June 2006 and May 2008, 30 out of 41 patients who were referred to the clinic were diagnosed with dementia. The contact rate at the Gnosall Memory Clinic represents three times that reported in hospital-based clinics. The clinic expedites diagnosis and also provides a 'local, non-threatening and non-stigmatised' care environment (Greening *et al* 2009, p 22).

Measuring quality

Currently, there is no widespread use of any tool seeking to examine the quality of dementia care within general practice. However, audit criteria have been developed by NICE/SCIE (2006b) for use by PCTs and social care providers as an audit tool on whether dementia guidance is being followed. The tool recommends using a sample of 100 people presenting with suspected or diagnosed dementia over a period of 12 months, utilising data extracted from patient health records. It suggests that audits should be repeated frequently, to assess progress towards compliance with the guidelines over time. The audit would be able to uncover the percentage of people suspected or diagnosed with dementia who receive care compliant with each criterion.

Ten criteria are provided to represent high-quality care in the NICE/SCIE (2006b) tool, though none specify any particular responsible 'provider' – such as general practice. In brief, the criteria are:

1. Percentage of people diagnosed with dementia where the health record shows criteria for meeting patient consent have been achieved.
2. Percentage of carers who have been offered an assessment of needs.
3. Percentage of carers whose assessment of needs has established experience of psychological distress and negative psychological impact and who have been offered psychological therapy, including cognitive behavioural therapy, by a specialist practitioner.
4. Presence of jointly agreed, documented policies and procedures for dementia services, across local health and social care providers (shared care).
5. Percentage of people with a possible diagnosis of dementia referred to memory assessment services.
6. Percentage of people with dementia who are service users with a documented combined care plan, where there is evidence that:

- the care plan has been agreed and, as appropriate, reviewed at an agreed frequency, to take account of any changing needs for the person with dementia or their carers
 - there is a named health and/or social care worker assigned to operate the plan
 - the care plan has been endorsed by the person with dementia and/or their carer.
7. Percentage of people with suspected dementia for whom structural imaging (computed tomography [CT] scanning or magnetic resonance imaging [MRI]) has been undertaken as part of assessment and diagnosis.
8. Percentage of people with dementia who develop non-cognitive symptoms that cause significant distress to the individual, or who develop behaviour that challenges, including agitation, for whom their care plan demonstrates that a comprehensive assessment has been undertaken to establish the likely causes and influences that may generate, aggravate and improve the behaviour(s), covering:
- physical health
 - depression
 - possible undetected pain or discomfort
 - side-effects of medication
 - individual biography, including beliefs, spiritual and cultural identity
 - psychosocial factors
 - physical environmental factors
 - specific behavioural and functional analysis conducted by trained professionals in conjunction with family carers and care workers.
9. An individual care plan has been developed to help carers and staff to address the behaviour that challenges, and is documented in the notes.
10. Dementia-care training is available for all staff working with older people in the health, social care and voluntary sectors, appropriate to their different roles and responsibilities. All health professionals within general practice, potentially including medical secretaries, to have the training and necessary skills to provide the best quality of care for their role in this setting.

In terms of incentivising quality care in general practice, the QOF provides points for producing a register of patients with dementia, and for the percentage of patients who have received a review in the past 15 months. One of our interviewees described this as a 'good starting place' for drawing attention to dementia care in general practice, but others felt the QOF does not currently motivate GPs and nurses to provide the high-quality care described above.

The potential impact of quality improvement

The financial impact of dementia is considerable. The total annual economic burden of late-onset dementia for England has been variously estimated from £14.3 billion to £20 billion, which is more than stroke, heart disease

and cancer combined (Alzheimer's Society 2007; Comas-Herrera *et al* 2007; NAO 2007a; Alzheimer's Society 2010). Direct health and social care costs for dementia account for £1.17 billion and £2.13 billion respectively. The majority of the total financial burden of dementia falls on the families and carers of people with dementia in terms of lost employment, lower earnings and lost pension entitlements (Alzheimer's Society 2007; NAO 2007a). The national cost of dementia is estimated to rise to £50 billion within 30 years (Comas-Herrera *et al* 2007).

Economic models show the potential financial benefits of commissioning services that deliver early diagnosis and intervention in dementia that prevent admission into care homes and so provide long-term cost savings (Banerjee and Wittenberg 2009). Early diagnosis and intervention has also been estimated to significantly increase quality of life, by diverting approximately 10 per cent of people with dementia out of care homes (Banerjee and Wittenberg 2009).

There are thus clear benefits to dementia sufferers and their carers in ensuring people with dementia receive high-quality care in general practice, since it plays a pivotal role in early diagnosis, referral and ongoing holistic care.

5 Depression

Depression was chosen as a condition to focus on for several reasons:

- It is highly prevalent in general practice.
- For many patients it is a long-term condition that follows a chronic or relapsing course.
- General practice is where most people with depression are treated – only 10 per cent are referred onto specialist services.
- There appears to be considerable scope for quality improvement.

Depression is a highly common condition. In the most recent national psychiatric morbidity survey, 11.3 per cent of adults in England met diagnostic criteria for a form of depressive disorder (McManus *et al*, 2008). An estimated 30 per cent of people attending primary care services have a mental health component to their illness – most commonly, depression and/or anxiety (Jenkins *et al* 2002).

The lay term 'depression' refers to a number of distinct diagnoses. For the purposes of this study we focus on unipolar as opposed to bipolar or 'manic' depression. In terms of ICD-10 diagnoses, we include both 'depressive episode' and 'mixed anxiety and depressive disorder'.

The severity of depression varies markedly. At its worst, it can have a profound effect on people's ability to lead normal lives. In terms of disability-adjusted life years, unipolar depression is responsible for more disability and suffering in high-income countries than any other health condition – accounting for 13 per cent of the total 'disease burden' among adults (WHO 2008).

In addition to its effects on individuals' lives, depression imposes a heavy cost at the societal level. In the United Kingdom, depression and anxiety are estimated to cost the economy £17 billion each year through a combination of sickness absence, reduced productivity and increased staff turnover. The cost to the Exchequer is estimated at £9 billion per year as a result of lost tax receipts and benefits payments (Layard 2006).

Depression is not evenly distributed across the population. Consistent positive associations have been found between mental ill health and various markers of social and economic adversity such as low education, low income, low social status, unemployment and poorer material circumstances (Melzer *et al* 2004). There is a two-fold variation in the prevalence of depression between the highest and lowest quintiles of household income (McManus *et al* 2009).

Depression is strongly correlated with physical illness. People with depression are twice as likely to have a stroke, and four times as likely to have a heart attack or develop heart disease, as people who are not depressed – even when other risk factors, such as smoking, are controlled for (Hippisley-Cox *et al* 1998; Sederer *et al* 2006).

Evidence suggests that for up to half of people who experience depression, the condition becomes a chronic or relapsing one. In a major international study, 50 per cent of people with depression still had depression one year later (Simon 2002). In a long-term follow-up study, 37 per cent of people

with depression and/or anxiety experienced chronic or relapsing illness lasting for at least a decade (Lloyd 1996). Other evidence suggests that at least 50 per cent of people who recover from a first episode of depression go on to experience another episode, and of those who have a second or third episode, 70 per cent and 90 per cent respectively have further relapses (Kupfer 1991). Outcomes are particularly poor for those who experience depression early in life (van Weel-Baumgarten 2005).

Such evidence suggests there is a case for managing depression like a chronic disease (Scott 2006; Tylee and Walters 2007).

However, while there is merit in discussing depression as a long-term condition, it should be borne in mind that depression has many features that make it different from physical long-term conditions such as arthritis, diabetes or asthma. Most important among these is the observation that the status of depression as a medical 'condition' is highly contested. It is arguable that the term actually describes a highly heterogeneous set of experiences rather than a single condition.

Ninety per cent of people with depression are managed solely in primary care. Furthermore, many of those referred to secondary care visit only once and then return to primary care. This indicates a need for high-quality care for depression to be provided within general practice.

What does high-quality care look like?

Three distinct dimensions to quality were identified in the literature reviewed:

- the interventions provided
- the organisational framework within which these are delivered
- the quality of relationships between the patient and professionals.

This section describes the evidence relating to each of these dimensions.

The overall framework for delivering high-quality care

For people who experience depression over extended periods of time (either continually or in recurrent episodes), high-quality care involves being supported by a planned system of support rather than accessing care on an ad hoc basis. Reviews (Kates and Mach 2007; Gilbody *et al* 2003; Oxman *et al* 2005; Boardman and Walters 2009; Barbui and Tansella 2006; Katon and Seelig 2008) indicate a need for a systematic framework that combines the following elements:

- case management, with a single individual responsible for co-ordinating different components of care, monitoring the patient's condition and ensuring follow-up
- a structured care management plan, shared with the patient
- scheduled patient follow-up
- systematic identification of patients with depression– for example, using screening tools among high-risk groups

- a multi-professional approach that involves a GP, specialists and a case manager
- the introduction of mechanisms to enable closer working between primary care and specialists
- patient education and support for self-management
- the development of patient registries.

A number of care models based on chronic disease management principles have been used to provide such a framework. The approach with the strongest evidence base is the collaborative care model. This has achieved improved outcomes in the United States (Gilbody *et al* 2003; Katon and Seelig 2008) and the United Kingdom (Richards *et al* 2008). A review of effectiveness trials found that the model achieves two-fold increases in adherence to treatment, improvements in outcome lasting between two and five years, and higher patient satisfaction (Katon and Seelig 2008).

The term 'collaborative care' has been applied to a number of slightly different models, but the most important elements appear to be case management, systematic follow-up and improved integration of primary and secondary care (Gilbody *et al* 2003). There are a number of questions around what shape case management should take.

- How much mental health expertise does the case manager need? Outcomes for depression may be best if case managers have mental health expertise (Bower *et al* 2006), but given the extent of co-morbidity it may be best if case managers are generalists (such as practice nurses) who can manage the patients physical health care as well as mental health care (Belnap *et al* 2006; Kilbourne *et al* 2004).
- How much supervision is required from specialists? Oxman *et al* (2005) suggest that case managers perform best where there is regular and systematic supervision by a specialist.
- What functions should case managers perform? The central task is to ensure that patients have adequate monitoring and follow-up, but in some cases the role has been extended to include delivering brief psychosocial therapies.

The draft NICE guidelines currently recommend the use of the collaborative care model only for those patients with depression alongside other co-morbid physical long-term conditions (NICE 2009a, 2009b). One interviewee suggested that in practice this distinction may not be workable:

Most of the people we see have got co-morbid problems... it's a false dichotomy, because you don't run two different services for people with depression with or without co-morbidity.

Primary care psychiatrist

It should be noted that some patients may find chronic disease management approaches overly intrusive, so these models may not be suitable for all. Similarly, while evidence suggests that systematic case finding may help identify people with depression who present to primary care with other, physical symptoms, screening tools (normally taking the form of a few short questions about emotional state) would need to be used tactfully and integrated with general consultation processes.

The interventions delivered

NICE guidelines define high-quality care in terms of what interventions should be delivered to patients with depression. The guidelines describe a stepped care approach, with a range of interventions recommended at each step. The two most prominent forms of intervention are anti-depressant medication and psychological therapy – in particular cognitive behavioural therapy (CBT) and interpersonal therapy (IPT). For many patients, the evidence suggests that broadly equivalent outcomes can be achieved with medication or psychological therapy, and that the best outcomes can be achieved by allowing patients to choose their preferred form of treatment (Lin *et al* 2005).

The evidence is there that if you give patients the opportunity to make a choice, that in itself is very empowering. One of the things about depression is that people feel out of control of their own lives... and by even offering them the choice of an intervention so that they begin to take a bit of control over their disorder, that in itself is therapeutic.

GP and policy adviser

Guidelines suggest that in addition to pharmaceutical and psychological interventions, social interventions should play a part in high-quality care. These may include exercise prescriptions, befriending, peer support or assistance with housing or employment issues.

High-quality care should also involve the use of self-management approaches, in which the clinician's role is not limited to providing support or treatment but also includes giving patients the skills and confidence to support themselves and manage their condition (Bachman *et al* 2006; Boardman and Walters 2009; Callahan 2001). The aim of such approaches should be to empower, educate and motivate patients, and not a simple sub-letting of care from the professional to the individual. This is particularly important in the case of depression, where disempowerment, passivity and learned helplessness can play a powerful and pernicious role in the life-course of the condition.

Relational aspects of high quality

In addition to providing effective interventions within a planned, supportive framework, high quality requires that attention is paid to the manner in which care is delivered – to what might be termed 'relational' aspects of quality.

High-quality care involves sensitivity towards the patient's perception of the cause and nature of the problem (including whether or not they conceptualise it as 'depression'), and their preferences about what the focus of intervention should be – whether ameliorating symptoms, increasing functional ability or resolving social or cultural difficulties (Dowrick 2009; Gilmore and Hargie 2000). Professionals and patients need to be able to construct a shared understanding about the diagnosis and treatment plan (Boardman and Walters 2009; Johnston *et al* 2007).

This requires health professionals to have good communication skills, and to structure their work in a way that allows them to deploy these skills. Research suggests that even patients receiving evidence-based treatment achieve better outcomes when those who treat them have good communication skills (van Weel-Baumgarten 2005).

The mental health literature stresses the importance of adopting a strength-based approach, which sees the purpose of mental health care not solely in terms of giving treatment but also in terms of enabling recovery – recovery being the process of building a life beyond illness (Boardman and Walters 2009). Tools are available to assist with this, such as Wellbeing and Recovery Action Planning (WRAP). Professionals involved in delivering care for people with depression need to be able to conceptualise their role as an enabling one, facilitating an individually defined process of recovery, and need the skills to do this effectively.

A further aspect of high-quality care for depression is relational continuity. The importance of continuity varies from one patient to the next, but for many the continued presence of one or more professionals throughout their experience is highly important.

What is the role of general practice?

General practice is often considered a gatekeeper to mental health services, but for people with depression of mild to moderate severity it is a service provider itself – indeed it is the only service that many will access. First and foremost, GPs need to accept that dealing with depression is a core part of their role and feel confident about doing this. The scope of this role needs to go beyond diagnosis, prescription and referral to include elements of the following:

- providing information and advice to allow the patient to understand and manage their condition
- signposting to different sources of support available, including those outside the NHS
- co-ordinating the support provided by different individuals, acting as a relationship broker
- providing relational continuity.

Some of these roles may be taken on by other staff within general practice rather than GPs themselves. Practice nurses, in particular, have an important role to play.

For those patients who need it, general practice needs to be able to provide continuing, organised support through a collaborative care model or similar. With training, practice nurses could act as case managers, and a range of other individuals could be brought in to provide interventions of varying intensities. When a referral is made to secondary care, ideally there would be an ongoing role for professionals in primary care rather than a complete transfer of clinical responsibility.

GPs cannot be expected to be experts in non-health issues such as housing or employment, but there is scope for GPs to signpost to relevant sources of support that are outside the health system but yet intimately related to a person's experience of depression:

We need to be sophisticated enough to deal with the individual who has several sorts of problems rather than making the patient fit into our bureaucratic silos – employment over there and debt over there – we need to do more about joining up our services.

GP and policy adviser

The current quality of care in general practice

The Royal College of General Practitioners acknowledges that while arrangements for treating acute mental illness are relatively well-developed, 'there is a lack of clarity about who should lead on the care of those with chronic, complex and disabling non-psychotic problems', such as depression (RCGP 2009). There is a perception that patients who experience depression over extended periods of time but who do not warrant referral to specialist services often fall through the gap between primary and secondary care. Research indicates that GPs feel less confident about managing patients with depression than they do managing those with physical long-term conditions (Ford 2006).

There is also evidence of under-treatment – in the 2007 national psychiatric morbidity survey, only 23 per cent of people meeting diagnostic criteria for a depressive episode, or mixed anxiety and depression, had received any form of treatment for this (McManus *et al* 2009). It is not clear how much of this relates to GPs' failure to diagnose versus patients not seeking help.

In primary care, the treatment provided most commonly for depression is anti-depressant medication. Surveys repeatedly demonstrate that many patients would prefer psychological therapy to anti-depressants, but access to this is often extremely limited:

Most GPs will see somebody and dish out some anti-depressants, and occasionally somebody will have the courage to ask for counselling and they might access it. And the follow-up would be pretty minimal.

GPSI in mental health

This situation is being addressed through the Improving Access to Psychological Therapies (IAPT) programme launched in 2007. Through this programme several thousand new therapists are being trained, and service structures are being created across the country. IAPT services will deliver time-limited CBT for up to 16 weeks, within a stepped care framework. Once the treatment period has been completed, responsibility for patients will usually be transferred back to primary care. IAPT will improve the quality of care in general practice for some people with depression, but will not be the answer for those for whom CBT does not lead to remission, and who need structured support over a longer period of time.

There has been very little adoption of chronic disease management approaches towards depression, and for most patients there is little systematic follow-up:

The natural history of depression care at the moment, people with chronic depression, they're going in and out of care, often with great big gaps in between, and turning up when things are bad, rather than having more planned regular systematic follow-up for their care in the way that the diabetic or an asthmatic would.

GP and academic researcher

Our expert interviewees suggested that often GPs already possess many of the right skills to provide high-quality care for people with depression but in some cases lack the confidence to do so. One concern is that clinical training may not adequately prepare GPs for dealing with mental health issues in primary care because psychiatric experience in specialist services is so

different from the sorts of mental health problems encountered in general practice. Several suggested that GPs often feared that becoming more involved with patients' mental health issues would be like 'opening a can of worms'. There may also be attitudinal barriers regarding the nature and treatability of depression:

We've done quite a bit of research on this, and I think there is still a lack of belief in depression as a disorder amongst quite a lot of GPs. They see it as a direct result of social malaise, and they say 'We can't do anything about social malaise.'... GPs actually have a very social model of mental health problems, which in some ways is quite a positive thing, but in other ways it's quite nihilistic because it means 'There's nothing I can do.'

Primary care psychiatrist

Measuring quality

Developing quality measures within mental health is notoriously difficult (Sharp 2003). However, it is possible to identify a mixture of structural, process and outcome measures relating to the three dimensions of quality discussed above, as set out in Table 2.

Table 2: Potential quality measures in mental health care

	Structure	Process	Outcome
Organisational framework for care	Provision of case management	Organisation of scheduled follow-up appointments	
	Existence of practice registries for depression	Creation of a written care plan, shared with the patient	
Interventions delivered	Accessibility of psychological therapy	Compliance with NICE guidelines	Clinical improvement
		Ability to choose between evidence-based interventions	Social inclusion
		Provision of self-management tools	Quality of life
Relational aspects of quality		Measures of continuity	PROMs
		Use of WRAP plans	Patient satisfaction
		Measures of therapeutic alliance	Measures of patient self-efficacy

It should be noted that the IAPT programme will provide a new source of data on access to treatment and outcomes, including broader outcome measures relating to social inclusion and return to employment.

The potential impact of quality improvements

There is a significant potential to improve the quality of care provided in general practice for people with depression. A key lesson is that there needs to be structural change to the way services are delivered: clinician education and training alone is not sufficient to deliver lasting improvement (Gilbody

et al 2003). However, organisational change will need to be coupled with cultural change – tackling attitudes regarding what depression is, and whose role it is to deal with it.

As described above, there are a number of efficacious models for improving the quality of care for depression. However, several barriers will need to be overcome if these approaches are to have a significant impact in practice.

- **Cost-effectiveness** This may be a barrier to implementation of the collaborative care model (Oxman *et al* 2005). Current evidence suggests the model may be cost-effective for major depression but not for milder cases (Gilbody *et al* 2003, 2006). A potential solution would be to embed collaborative care within a stepped care model, reserving full support only for patients who want and/or need it.
- **Professional relations** Models such as collaborative care work best when built on pre-existing clinical relationships (Kisely and Campbell 2007), and when there are already good relationships between primary and secondary care (Gilbody *et al* 2003). In many parts of the NHS, these relationships are not as close as in the US managed-care organisations within which these models were developed. GPs may not feel confident enough to accept more responsibility for depression care without the specialist supervision and support that the collaborative care model suggests is required.
- **Stigma** Stigma and taboos surrounding mental health issues may mean that community support that exists for physical long-term conditions may not be present in the case of depression (Croghan *et al* 2006).

If these barriers are not addressed, they may act to reduce the impact of the changes proposed.

6 Diabetes

Diabetes (diabetes mellitus) is group of chronic and progressive disorders characterised by elevated blood glucose. Raised blood glucose occurs either when a person cannot produce insulin and/or cannot respond to it (Department of Health 2002). There are different types of diabetes, including the most commonly occurring types, on which this chapter focuses: type 1 and type 2.

- Type 1 diabetes is non-preventable, and develops if the body is no longer able to produce insulin (Department of Health 2002). Blood glucose builds up in the body and is passed out of the body in urine, causing increased thirst, tiredness and blurred vision. Type 1 diabetes develops most frequently in children, young people and young adults (Diabetes UK 2010). It is less common than type 2 diabetes, and makes up 5–15 per cent of total diabetes cases in England. The prevalence of type 1 diabetes is increasing in all age groups, but particularly among children under five (Gardner *et al* 1997). Treatment is based on daily injections of insulin and modification of diet and lifestyle to ensure that blood glucose levels are maintained at a 'normal' level.
- Type 2 diabetes develops if insulin-producing cells are not able to produce enough for the body's needs. Most people with type 2 are also resistant to insulin, or do not respond to insulin produced in the body (Department of Health 2002). Excess body fat is thought to be one risk factor for developing diabetes, as this causes cells to become less responsive to insulin.

Between 85 and 95 per cent people with diabetes have type 2. It usually occurs among people over 40 years of age, although it can occur after the age of 25 among South Asian and African-Caribbean people (Diabetes UK 2010). Treatment is based on lifestyle changes, such as losing weight, increasing levels of physical activity and modifying one's diet. Type 2 deteriorates over time which means that diet and exercise alone may become ineffective, in which case medication is prescribed to help the body break down glucose.

Diabetes is associated with other health problems in the long term (YHPHO 2008) including:

- cardiovascular diseases, such as heart disease or stroke
- retinopathy
- nephropathy
- neuropathy
- circulation problems
- depression.

The risk of developing physical health complications can be reduced by controlling blood glucose and cholesterol levels, being physically active and attending regular medical examinations and screenings. This requires

people to carry out a degree of self-management and requires health care professionals to ensure the condition is monitored.

In 2008, the Yorkshire and Humber Public Health Observatory (YHPHO) estimated that more than 2.4 million people in England had diabetes (either diagnosed or undiagnosed) (YHPHO 2008). The rate of diabetes will continue to rise, due to the rising rate of obesity and the ageing population. The YHPHO forecasts that by 2025 the number will have risen to more than 3.6 million (about 6.5 per cent of the population).

Diabetes is more likely to occur in areas experiencing greater levels of deprivation. The rate of diabetes complications is 3.5 times higher among people in social class V compared with those in social class I. People in deprived communities are more likely to be overweight or obese and physically inactive. Also, there is a strong association between deprivation and poorer blood glucose control, worse access to services, and referral bias. More men develop diabetes than women. However, diabetic women appear to be at relatively higher risk of dying than diabetic men (Department of Health 2007b).

People of South Asian and African-Caribbean descent in England are six and three times more likely (respectively) to have type 2 diabetes (Department of Health 2007b). Diabetes is also more common among people of Chinese descent and other non-Caucasian groups. Susceptibility to cardiovascular disease and retinopathy and the risk of mortality from diabetes is higher among black and minority ethnic groups (Department of Health 2007b).

People aged between 20 and 79 years who have diabetes are twice as likely to die as people without the condition. Among people with diabetes, the hazard ratios of dying are higher for those under 60 years of age, and the hazard ratios are higher for women than for men in all age groups (YHPHO 2008).

The impact of diabetes on the health care system is substantial. The total NHS expenditure on the diabetes care programme in 2006/7 was £1,043 million. Over half of this was accounted for by prescribing costs (YHPHO 2008). Diabetics are twice as likely to be admitted to hospital as others, and it is estimated that prolonged hospital stays among diabetics result in approximately 80,000 bed days per year (Sampson *et al* 2007). In 1998, nearly 6 million working days were lost due to diabetes in England and Wales. This would have cost £256 million in lost productivity (YHPHO 2008).

What does high-quality care look like?

For people who have been diagnosed with diabetes, there are a range of best-practice guidelines, an NSF and core standards of care written into the QOF payment system. The NSF for diabetes details an approach to improve service quality and reduce variations in care by setting national standards for diabetes care, ranging from prevention (of type 2) to the detection or management of long-term complications (Department of Health 2003 – see the box below/overleaf).

The NSF includes milestones, set to ensure that all people with diabetes are identified on an up-to-date register and offered annual retinal screening, and that a system of regular follow-up was followed to ensure that diabetic

patients were given the appropriate information, education and advice to help them support self-care.

NSF for diabetes: core standards

Standard 1: Prevention of type 2 diabetes

Standard 2: Identification of people with diabetes

Standard 3: Empowering people with diabetes

Standard 4: Clinical care of adults with diabetes

Standards 5 and 6: Clinical care of children and young people with diabetes

Standard 7: Management of diabetic emergencies

Standard 8: Care of people with diabetes during admission to hospital

Standard 9: Diabetes and pregnancy

Standards 10, 11 and 12: Detection and management of long-term complications

Source: Department of Health (2003)

NICE published best-practice guidance for type 1 diabetes in 2004 and updated it in 2010 (NICE 2004, 2010). The guidance set key priorities for treating type 1 diabetes for children and young people including:

- patient education
- prevention of diabetic ketoacidosis
- screening for complications and associated symptoms
- psychosocial support.

The guidance also set key priorities for treating type 1 diabetes in adults, including:

- education – for example, the Dose Adjustment for Normal Eating (DAfNE) course
- control of blood glucose and arterial risk factors
- dealing with late complications.

NICE provided best-practice guidelines for type 2 diabetes in 2008 (NICE 2008c). The guidance makes more than 100 recommendations for the different aspects of managing the condition. Among others, these included:

- education – for example, the Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND) course
- dietary advice
- managing depression
- setting targets with the patient
- clinical and self-monitoring
- oral medication and insulin prescription

- blood-pressure reduction targets
- monitoring cardiovascular risk, kidney, eye and nerve damage.

Common to both sets of guidance was the need for care and treatment to be delivered through a multidisciplinary team approach. This has been re-emphasised in guidance on the commissioning of diabetes services – the Diabetes Commissioning Toolkit (Department of Health 2006a) – and the policy *Making Every Young Person and Child with Diabetes Matter* (Department of Health 2007a).

Further articulation of the shared care model of service provision was developed in the Year of Care initiative, established by the Department of Health and Diabetes UK. The Year of Care sets out a pathway that aims to make consultation between people with diabetes (and other long-term conditions) and clinicians a more collaborative process, through personalised care planning and co-ordination. These care plans are intended to give the individual greater ownership of the management of diabetes through joint decision-making with health care professionals, in a way that makes it more relevant to their needs.

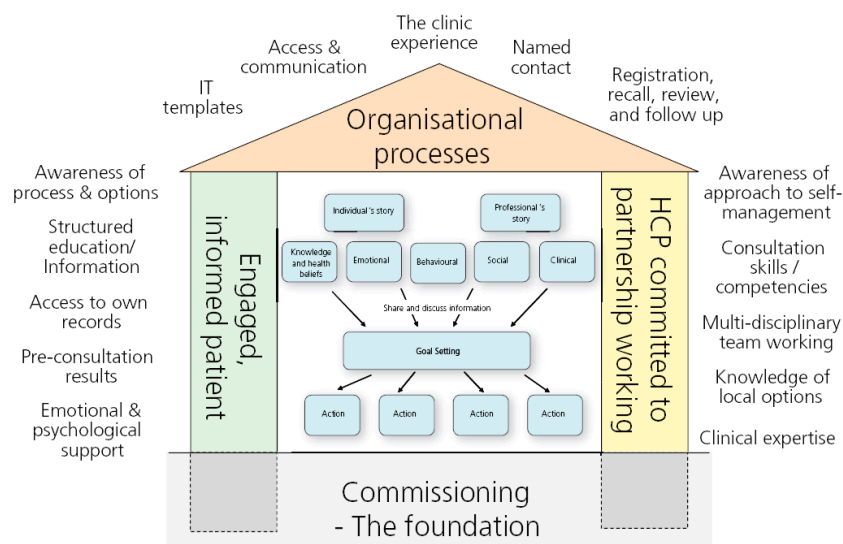
The experts interviewed as part of the Inquiry commonly reported that the Year of Care approach to diabetes management was approaching what best practice should look like, since it emphasised the roles that generalists and specialists alike should play in a person's ongoing care. They emphasised how awareness of options, training and advice about diabetes management should be available to staff who provide health care services. This was particularly necessary for staff working out of hours, where a lack of care continuity and experience might increase the likelihood that people with diabetes will be admitted to hospital when crises occur.

The need for effective care planning was another strong theme to emerge from the expert interviews – particularly where individuals had other complex care needs:

What we're talking about is a discussion between the health care professional and the patient about what's important to both types. So, actually, if the doctor's main thing is to get the patient to stop smoking but the patient's main problem is they're about to be evicted from their home, they're not going to listen to the 'give up smoking' advice. So you've got to have a discussion about what are the goals.

Representative of national diabetes charity

A diagrammatical representation of the components of the care planning process has been developed for people with diabetes, and is reproduced as Figure 2, below.

Figure 2 The components of care planning for people with diabetes

Source: Diabetes UK *et al* (2008, p 19).

Another key theme emerging from our interviews with experts was the expectation that in high-quality care, the patient would be supported to take responsibility for the self-management of their condition as set out in their care plan – for example, in terms of their ability to self-monitor and manage their blood glucose levels, weight and medication. The participants considered that providing information and support tools to enable patients to self-care was an important pre-requisite to achieve this, and reported that such information was already well advanced and available – for example, through access to the DAFNE and DESMOND courses.

As with other long-term conditions, expert informants argued that effective care for people with diabetes requires a long-term relationship between the individual and a range of health care professionals – not just those working in general practice. They regarded regular, streamlined contact between the individual and the health care team as being important for those with needs requiring multi-disciplinary care.

What is the role of general practice?

It was clear from the best-practice guidance and the expert interviews that general practice plays a pivotal and significant contribution to the effective management of diabetes, but that the nature and extent of their role and contribution in partnership with other care providers was less well articulated. At one level, a key role for general practice was seen as providing health promotional support to patients in order to help prevent the onset of diabetes. This took the form of providing advice and support to those with high risk factors, such as people who were overweight/obese and those with a family history of diabetes. Based on such assessments, the GP could consider referring patients for screening – for example, to examine impaired glucose tolerance – and could then follow this up with an appropriate intervention, such as lifestyle changes or medication (Gillies *et al* 2008).

As the report to the Inquiry by Boyce *et al* (2010) suggests, general practice cannot of itself deliver interventions that prevent the onset of conditions

such as diabetes, but they are well placed to at least provide information to encourage positive lifestyle changes, or to refer at-risk patients to appropriate support services.

The best-practice guidance, literature evidence and expert interviews suggest that the role of general practice should encompass the following key tasks.

- **Awareness of risk factors and symptoms** General practice professionals play the key role in recognising the symptoms of diabetes in patients and making an appropriate diagnosis.
- **Prompt and appropriate referral** For example, in cases where symptoms of type 1 diabetes are suspected in children and young people, GPs must make an immediate (same-day) referral to a multidisciplinary paediatric diabetes care team. The team can then confirm the diagnosis and begin immediate care.
- **Holistic assessment** The general practice team, in partnership with specialists, should be responsible for carrying out an holistic assessment of the patient, taking into consideration factors such as social support and employment (if applicable) as well as medical risks and needs. The assessment should be multi-disciplinary so that professionals and patients are aware of any co-morbidities and so can make referrals for further investigation and treatment if necessary. The GP can prescribe the relevant medication and be aware of any other medication prescribed to the patient by other health care professionals.
- **Information and advice** The GP must relay his or her diagnosis to patients honestly and clearly, so that they understand what diabetes means and how it will be managed. It may be appropriate to provide high-quality, individualised information about diabetes and healthy lifestyle changes, or to explain how the patient can access it themselves. In addition, the GP can make a referral for the patient to attend an education course such as DAFNE or DESMOND.
- **Personalised care planning** The care plan should ideally be a product of a supportive discussion between the professional and the patient about the goals for controlling diabetes and any related complications and healthy lifestyle changes. The professional has to consider what is realistic and achievable when discussing the care plan and should be willing to listen to the patient's point of view.
- **Ongoing monitoring and follow-up** Typically undertaken within general practice by nurse specialists or health care assistants, practices need to ensure that regular checks are made of the patient's blood glucose, blood pressure, cholesterol, weight, albumin level, creatinine level and foot care. They should ensure that the patient is referred for retinal screening and should encourage them to keep their appointments by emphasising their importance.
- **Emotional well-being** NICE guidance suggests that professionals working in general practice are responsible for the emotional well-being of patients as well as their physical health, and so should be alert to the development or presence of depression and/or anxiety

– particularly where this is impeding the individual's ability to self-manage.

- **Multi-disciplinary working** The needs of diabetes patients appear to be better met when staff in general practice work with specialists and other care providers in multi-disciplinary teams – particularly during the process of assessment and care planning. Good communication, open dialogue and shared information about patients between care providers also appears to help in providing patients with a better and more streamlined experience across the care pathway.

The current quality of care in general practice

Our review of the literature and interviews with experts suggests that some aspects of diabetes management have improved recently in general practice. The introduction of the NSF, NICE guidance and the QOF all supporting this improvement in care standards. However, the quality of care remains variable across England, and rarely meets all the aims of the 12 NSF standards and NICE best-practice guidance.

The proportion of people receiving all care processes has increased substantially over the past few years, yet for 2008/9 it was estimated that just 51 per cent of people with type 2 diabetes and 32 per cent of those with type 1 diabetes received all NICE-recommended care processes. This implies that 49 per cent and 68 per cent (respectively) did not (NHS Information Centre 2010). Meanwhile, compared to the Department of Health's NSF target of 100 per cent of diabetic people being offered an eye test for retinopathy by the end of 2007, in 2007/8 only approximately 65 per cent had received it (NHS Information Centre 2008). Similarly, where care processes are being carried out, there is variation in terms of type 1 versus type 2 (NHS Information Centre 2008, 2010), and there appears to be variation in terms of ethnicity (Soljak *et al* 2007; Gray *et al* 2007).

Generally, however, standards have improved. There has been an increase in recording of people with diagnosed diabetes in England since 2005 (YHPHO 2008), although an estimated 14 per cent of the total number of diabetics in the England remain undiagnosed. The expert informants provided anecdotal evidence that many GPs do not have enough experience of children and young people with type 1 diabetes to recognise symptoms in order to ensure an early diagnosis.

In terms of monitoring the physical health of people with diabetes and ensuring care processes are carried out, there have been some improvements in the quality of diabetes care, but these do not apply to all people. Studies have revealed inequalities in the recording of diabetes at general practices. For example, a short time after QOF was introduced, analysis of records from 237 general practices in England, Scotland and Wales showed that patients living in more deprived areas were less likely to have HbA1c, body mass index and smoking status recorded (Hippisley-Cox *et al* 2004).

As we have seen, many of the processes for the management of diabetes have been written into the QOF. The evidence from the QOF database shows that practice improved quickly in meeting the quality of care targets for people with diabetes in general practice – particularly those in more deprived localities whose performance was weakest (Campbell *et al* 2007; Tahrani

et al 2008). This analysis was extended to include performance data and examine a time-series effect between 1998 and 2007. This showed that the quality of care for diabetes had been increasing pre-QOF and then increased significantly following its introduction. However, the accelerated rate of improvement was not sustained after 2005, when it reduced to the pre-QOF rate (Campbell *et al* 2009).

The lack of initiation and implementation of care plans in general practice was a major issue for concern among the experts we interviewed, and the evidence suggests that this would be a significant area for improvement. They reported a view that professionals in general practice are not always able to develop care plans in partnership with patients or to provide the encouragement and motivation needed to ensure goals are met. In part, they saw this as being due to a reluctance among GPs and nurses to ask questions about why patients have not been able to meet certain goals or how the patient is feeling, because they are reluctant about 'opening a can of worms'.

In such cases, GPs and nurses could benefit from training in motivational interviewing skills, as highlighted in the report to the Inquiry by Greenhalgh and Heath (2010):

Logic alone suggests to me that if somebody has diabetes and they're having to look after themselves 97 per cent of the time, and they only need a health care professional 3 per cent of the time, they actually are much more an expert on their own care than the person they are consulting. So logic would suggest that the health care professional needs to be able to listen to what's important to that person. And... what's important to them changes all the time. So the concept behind the care planning approach, which is collaborative and partnerships and equal and informed, to me makes an enormous amount of logical sense. And those cultural skills, I believe, are not necessarily engrained in every GP or practice nurse.

NHS Diabetes stakeholder

The written evidence seems to support a lower-than-optimal level of care planning with diabetes patients. For example, a Diabetes UK survey of PCTs in 2007 showed that only 67 per cent required a care plan to be made (Diabetes UK 2008). Similarly, a review of health care services by the Healthcare Commission (2007) showed substantial variation in care planning across PCTs in England. The proportion of people with diabetes who reported having discussed their care plans and agreed self-care goals ranged from a low of 23 per cent to a high of 58 per cent.

Another strong theme to emerge from the research evidence is the need to share good information between professionals, in order to help them understand and respond to a patient's needs. It was felt that there were sometimes barriers to GPs and nurses accessing the information they need in sufficient time to provide this to patients, and that there are no easy methods for sharing information between general practice and specialist teams. This lack of integration means GPs and nurses cannot easily ask for advice about diabetes management or find out about medication prescribed to the patient by other teams.

Experts were also concerned about patients' access to high-quality information about diabetes and its management. For example, evidence from a Diabetes UK survey suggests that 23 per cent of its members (from

13,276 respondents) felt that improved access to information would improve their diabetes care (Diabetes UK 2009). An expert from the same charity, interviewed in this study, reported that patients often do not recall being given information by their GP or practice nurse. Therefore even if information has been given verbally or in written format, people do not necessarily retain it. People with diabetes need information to support them in making changes to their lifestyle and diets.

Measuring quality

Relative to other long-term conditions, there is a robust set of guidelines for best practice in the management of diabetes, and a number of best-practice measures and indicators that are collected to monitor and manage quality. However, the evidence shows these have not necessarily been successful in ensuring that people with diabetes receive high-quality and equal care for every component of their care needs, indicating the need for improvement in the quality of diabetes care management in general practice and in the multi-disciplinary care teams it should be working with.

Despite QOF leading to generally improved results in terms of diabetes care, the experts interviewed were in agreement that QOF had been more beneficial for 'putting diabetes on the map' than in making a step change towards better care management overall:

QOF isn't perfect, but it's changed the way diabetes care is managed in primary care... I think things are being done which weren't being done before it was there... a financial reward is the thing that works best, unfortunately.

Representative of national diabetes charity

However, the QOF quality indicators do not entirely reflect the combined picture of high-quality care provided in best-practice guidance. This suggests that the scope of QOF is not broad and flexible enough to incentivise key elements of best practice in general practice, including:

- the encouragement of type 2 diabetes prevention by addressing obesity and sedentary lifestyles
- the encouragement of achieving individual targets for HbA1c (which may be above the general target of 6.5 per cent set for people with type 2 diabetes)
- the provision of holistic care of the patient with diabetes
- the encouragement and facilitation of self-management
- the ability to work with other care providers in multi-disciplinary teams.

The potential impact of quality improvements

Efforts to improve the quality of care in the areas mentioned above are potentially beneficial to the health care system, the economy and individuals. Although robust cost-effectiveness data from long-term studies on diabetes care are lacking within a UK context (Simmons *et al* 2010), there is consensus that preventative measures in primary care (such as impaired glucose tolerance screening and medication or motivational interviewing)

have the potential to reduce the risk of diabetes in the community, and appear to be cost-effective (Gillies *et al* 2008; Greaves *et al* 2008; Waugh *et al* 2007).

7 Managing people with multiple long-term conditions

So far, this report has discussed high-quality care for people with a single long-term condition. However, a substantial proportion of people with long-term conditions experience co- or multi-morbidity – the presence of two or more conditions simultaneously. Indeed, research evidence suggests this is more often the rule than the exception. One study of patients attending general practice in Canada found that 69 per cent of 18–44 year olds, 93 per cent of 45–64 year olds and 98 per cent of those aged 65 and over had two or more long-term conditions (Fortin *et al* 2005a). As well as increasing with age, there is evidence that multi-morbidity is more prevalent among minority ethnic groups and groups with lower socioeconomic status (Ogle *et al* 2000).

A particularly common form of multi-morbidity is the existence of mental health problems such as anxiety or depression, or neurological problems such as dementia, alongside physical health problems such as diabetes, arthritis or cardiovascular disease (Chapman *et al* 2005; Evans *et al* 2005; McVeigh *et al* 2006; Roy-Byrne *et al* 2008). For some conditions, the association between mental and physical health is very strong. For example, in the United Kingdom depression has been associated with a fourfold increase in the risk of heart disease, even when other risk factors such as smoking are controlled for (Hippisley-Cox *et al* 1998; Osborn *et al* 2007).

Co-morbidities are also common between physical long-term conditions. For example, people with arthritis are twice as likely to suffer from obesity or heart disease as people in the general population, even after adjusting for age, sex and class (Kadam *et al* 2004). Similarly, people with diabetes are at increased risk of stroke (Mulnier *et al* 2006).

The impact of multi-morbidity is profound and multi-faceted. Patients with several long-term conditions have poorer quality of life, poorer clinical outcomes, longer hospital stays and more post-operative complications, and are more costly to health services (Fortin *et al* 2007). For example, diabetic people with co-morbidities show poorer adherence to treatment, more complications, and increased use of medical care relative to people with diabetes alone (Chapman *et al* 2005; Evans *et al* 2005; McVeigh *et al* 2006; Strujis *et al* 2006). There is evidence that the degree of multi-morbidity can be a greater determinant of a patient's use of health service resources than their diagnosis (Starfield *et al* 2003).

What does high-quality care look like?

There is little direct evidence demonstrating what would represent high-quality care for people with multiple long-term conditions – not least, because most research trials specifically exclude people with multi-morbidities. What research has been done on multi-morbidities is mainly epidemiological work looking at the prevalence and distribution of multi-morbidity rather than interventionist work testing ways of providing care for these people (Fortin *et al* 2005b). Furthermore, clinical practice guidelines generally have a single-disease focus, and fail to discuss the applicability of their recommendations to people with multiple conditions (Boyd *et al* 2005). They are therefore of limited use for describing high-quality care for such

people. An exception to this is the new NICE guidelines for the management of depression in people with chronic physical health problems (NICE 2009b), described in the following paragraph.

What evidence does exist suggests that a patient-centred approach that addresses a person's various needs in an integrated way leads to better-quality care. For example, collaborative care models that integrate mental health and primary care lead to better depression outcomes for people with medical co-morbidities (Narasimhan *et al* 2008). The draft NICE guidelines for the management of depression in people with chronic physical health problems (NICE 2009b) recommend that collaborative care models are used for more severe cases of depression, with case management, systematic follow-up, close collaboration between primary and secondary care, and co-ordination of mental and physical health care.

A promising model of care developed specifically for people with multiple conditions is the guided care model (Aliotta *et al* 2008). This is essentially an extension of the collaborative care model, with particularly intensive case management, featuring an emphasis on:

- self-management and carer support, comprising several hours of training for patient and carer alike, focusing on managing multi-morbidity
- home-based assessment of patient
- transitional care, comprising close, structured support through transitions in care (for example, after discharge from hospital)
- care managers trained in motivational interviewing
- predictive modelling, to identify multi-morbid patients.

Early evidence suggests that guided care can improve the quality of health care for people with multiple long-term conditions, although this evidence is US based, and relates mainly to older people (Boult *et al* 2008; Boyd *et al* 2008).

Several studies explore what people with multiple conditions want from their health care. Continuity of care appears to be particularly important, both in terms of relational and management continuity (Cowie *et al* 2009). Indeed, the value that patients place on continuity increases with the number of co-morbidities (Nutting *et al* 2003).

A key area of concern is around potential adverse interactions between medications prescribed for different conditions. Qualitative evidence suggests that these can have a significant impact on people's lives (Noel *et al* 2005). The NICE guidelines state that prescribers should be vigilant for such interactions (NICE 2009b).

Self-management approaches are also important, with evidence indicating that willingness to learn such approaches is higher among people with multiple conditions than among those with a single condition (Noel *et al* 2007). In particular, people with multiple conditions express the need for approaches that enable them to manage their medications, cope with stress, manage pain, and change their diet and lifestyle (Noel *et al* 2005). Our expert interviewees stressed that this support should go beyond providing written information, and should aim to genuinely empower patients:

There are two radically different versions of self-care. The first, which is most commonly used in medicine (general practice in particular) is getting patients to do stuff that doctors haven't got the time or energy [to do], or can't be bothered to do themselves. So it's a sort of a sub-letting of care from the professional to the patient... [The second] is about a view of patients as people who can organise and lead their lives and sort things out.

GP and academic researcher

There may be some scope to exploit synergies by identifying interventions of mutual benefit for several conditions. For example, dietary change and exercise prescription is recommended for treatment of depression (NICE 2009a, 2009b) and can also be expected to help in the management of some physical long-term conditions.

Multi-morbidity also poses a challenge to methods used for case finding. Chronic disease management approaches that identify patients on the basis of the severity of a single condition may miss multi-morbid patients who would stand to benefit greatly from improved co-ordination of care (Starfield *et al* 2003).

What is the role of general practice?

The various challenges posed by multi-morbidity underline the importance of generalists in the health care system, and suggest that there is a need for changing the role of general practice to develop new ways for primary and secondary care can work together more closely (Starfield *et al* 2003).

Our expert interviewees agreed that there is an important role for general practice in supporting people with multiple long-term conditions rather than transferring clinical responsibility to specialist teams. However, as many of these patients are likely to need specialist input at least some of the time, the interface between general practice and specialist care is also crucial:

I think general practice has got a very important role. But there are, obviously, interface issues: people do go into hospital, and do need to be brought home again in a timely way and with the right care and support around them. So those interface issues are very important.

Department of Health programme lead

There is a particularly strong case for case management for people with multiple long-term conditions, to provide the relational continuity and co-ordination of care that the evidence suggests is highly important to this group. General practitioners themselves may not need to take on this role – practice nurses or community matrons may be more appropriate – but GPs will need to work closely with whoever does provide case management, and to maintain clinical responsibility for the patient. (For more detail on this point, see Section 8, p 61.)

In most places it's not a good use of GP time to deliver chronic disease case management because it's expensive, so a nurse is better, better skilled, [and] more cost-effective and efficient at doing it.

Nurse practitioner with a special interest in depression and LTCs

[GPs] do need to draw in the help of other people, whether it's their practice nurse, local community nursing service, local diabetic nurse... whoever it is... But the GP – I think – has to, sort of, hold the ring.

Department of Health programme lead

Medicines management forms a core part of the GP role in providing care for people with multiple long-term conditions. GPs should be aware of the potential for drug interactions, and for poorer compliance with treatment among these patients. There is a strong case for GPs to provide access to self-management tools that assist with medication management and other aspects of patients' lives.

Our interviews highlighted the need for GPs to pay particular attention to the psychological and emotional aspects of physical long-term conditions, as well as to the physical health care of people with long-term mental health problems. The interviewees saw identifying and responding to patients' psychological needs in primary care as being vital to improve the quality and cost-effectiveness of care. This may include screening people with physical long-term conditions for psychological and mental health problems:

There are a whole range of issues where managing the psychological consequences of the long-term condition improves the outcome. When long-term conditions account for 70 per cent of NHS expenditure, not looking at the psychological consequences that would improve their management is downright bonkers... The economic case, as well as the moral case... is just so strong.

GP and policy adviser

It should be something that's automatically considered when someone has long-term conditions. Automatically after someone's had a stroke, automatically after someone's had heart problems, [there should be] some screening and expectation that they will need some advice around depression.

Mental health nurse and policy adviser

I think that's the big thing that's missing from not just primary care but all care, is that sort of emotional, psychological aspects of care, it's totally under-resourced, and in any long-term condition, no matter what it is, that element needs to be provided, and the primary care would be a very good place to provide that at a certain level.'

Director, voluntary sector organisation

The current quality of care in general practice

There is evidence that people with multiple long-term conditions get poorer treatment from health services. People with depression in addition to heart disease have lower rates of revascularisation surgery than people with heart disease alone despite equivalent clinical need (Kisely *et al* 2007), while also having poorer access to care for their depression than people with depression alone (Nuyen *et al* 2008).

People with multiple conditions may suffer from (Noel *et al* 2005):

- adverse interactions between drugs used to treat different conditions
- being perceived by service providers as 'problem patients'

- non-recognition of a co-morbid condition due to it being overshadowed by an existing diagnosis.

Several studies have found that people with multiple conditions experience more aggravation in interacting with the health care system (Noel *et al* 2005; Parchman *et al* 2005). Patients report disagreements between them and their doctor regarding which of their health problems is most important and requires attention first. Some report that consultation times are not always sufficient to allow their multiple conditions to be discussed (Noel *et al* 2005).

In the case of patients with physical long-term conditions and co-morbid mental health problems, developing high-quality care may currently be impeded by a lack of clinicians who have skills in both mental health and long-term conditions:

What we lack are psychological therapists with a knowledge of some of those co-morbid physical illnesses or [of] working with chronic illness.

Primary care psychiatrist

Measuring quality

Potential measures of quality of care for people with multiple long-term conditions are similar to those that exist for people with single conditions. However, the evidence suggests that particular emphasis should be given to developing quality measures that relate to the following dimensions:

- continuity
- access to self-management approaches
- structured support for carers
- integrated treatment of physical and mental health care needs
- provision of case management
- absence of adverse interactions between drugs.

Such measures of quality are hard to measure and quantify, and so most would not lend themselves to indicators for use in a balanced scorecard or QOF-based system of quality assurance. The QOF does contain some measures that are of relevance to co-morbidity (particularly in linking screening for depression to conditions such as diabetes). However, achieving high-quality care for people with multiple long-term care needs is unlikely to improve unless these wider dimensions of quality can be valued, measured and used to represent how care quality is being achieved. Moreover, these measures should be applied not just to the general practice, but across providers who have a shared care role in managing people with multiple long-term conditions.

Given the importance of achieving high-quality and cost-effective care for people with multiple LTCs, there is a need to develop more effective ways of measuring, comparing and reflecting on performance. We return to this issue in our conclusions (Section 10), where we outline a number of possible ways in which these quality domains might be measured to enable quality improvements to be made.

8 Managing long-term conditions across a population

Relatively well-defined disease-specific pathways are in place for individuals with certain diagnoses – and, to a lesser extent, for those with multiple long-term conditions. However, these approaches still rely on the patient seeking out treatment. Such approaches can result in reactive episodic care, where a patient only seeks help when in crisis.

One means of addressing this is population management – an approach that seeks to reduce expensive and distressing emergency admissions, by promoting high-quality proactive care for patients. The term refers to any strategic activity that attempts to proactively identify individuals at risk of deterioration in the future, with the intention of preventing or slowing that deterioration. It is based on the theory that early intervention has potential to reduce downstream utilisation.

This section considers what evidence there is for population management. It examines the structures and interventions that could be put in place, and are being put in place, to proactively manage patients with long-term conditions. Finally, it seeks to define what the role of the GP might be in a population management programme.

Evidence for population management in primary care

The LTC model outlined at the beginning of this report emphasises the importance of upstream interventions in primary and community care that can enable downstream resource savings, by maintaining well-being and avoiding costly and distressing unplanned admission. The model recognises that only a small number of patients will require high-intensity care, and that it is possible (and necessary) to stratify a population into different risk categories. These range from the very high-risk patients, who need high-intensity case management, through patients who are moderately high users of health services and who might need some support to self-manage, right down to individuals who are not yet deemed high risk but who might become high users of care in future.

Although the NSFs and NICE guidance have been useful in setting standards for individual pathways of care once a diagnosis has been reached, population management advocates moving a step further upstream, to assess whole-population needs, with a view to targeting different interventions at individual risk groups.

Evidence as to the quality and cost-effectiveness of such an approach is rather patchy. What is clear from the evidence is that a population management model must consist of two elements.

- There must be a reliable way of effectively stratifying a population in order to identify which patients in a population will be at high risk of emergency admission to hospital in future.
- Once the level of risk of admission is identified, there must be an appropriate and cost-effective intervention that reduces the individual's risk of emergency admission and promotes patients' ability to become less dependent generally on health care interventions.

Identifying the right patients

Evidence from the United Kingdom and the United States suggest that accurate identification of patients appropriate for interventions is crucial to the success of any population management programme (Billings *et al* 2006b). Without a reliable method of stratifying populations into risk groups, it is likely that care will be targeted at patients who do not need the care, and will potentially miss those who do.

A case in point is the Evercare pilot in the United Kingdom, whose evaluation indicated that the programme cost over £3.7m yet had 'no significant effect ... on rates of emergency admission, emergency bed days, or mortality' (Boaden *et al* 2006). Some commentators surmised that the lack of impact could be at least partly explained by the fact that the case-finding method did not identify the correct patients (Gravelle *et al* 2006). This was due to a phenomenon known as 'regression to the mean' (identifying patients at the height of their usage of medical care, rather than those most likely to be high users in the future), and it is imperative that any method of identifying risk takes this issue into account (Curry *et al* 2005).

Various predictive models are now available to the NHS. Availability of, and access to, data is key to these models. Some of those models (for example, The King's Fund's PARR and Dr Foster's HUM) use only inpatient data to predict risk of re-admission among the highest-risk population, while others (for example, the combined predictive model) link GP data with hospital data, to stratify an entire population from very high risk to low risk.

Some commentators argue that the use of GP data models has the potential to have a greater impact on admissions, by enabling intervention much further upstream (Wennberg *et al* 2006). If timely data is available, such models also enable real-time identification of at-risk patients in practice settings, so that practice-based teams can target follow-ups and make appropriate interventions quickly and effectively to patients on their list.

What has emerged in recent years is the importance of having high-quality data available for needs assessment and service planning. In this context, GP data-based models offer a much richer insight into the needs of a population. Competency 5 in the world class commissioning documents cites predictive modelling as an integral part of 'managing knowledge and assessing needs' (Department of Health 2007b). The move to GP commissioning from 2010 onwards is likely to promote further the need for such information. The role of general practice in keeping and providing high-quality data and information (in order to support predictive risk tools that help target case management at appropriate individuals) seems to be a highly important issue for the future.

Developing an effective intervention

The second element of population management is the development of appropriate and cost-effective interventions that reduce the risk of admission, or re-admission, among individuals in each risk segment. Evidence of what interventions might be effective is beginning to emerge but is, at present, very limited. Several different initiatives exist or are being piloted, including:

- case management through community matrons

- telehealth and telecare
- telephone health coaching
- collaborative care models.

Such interventions vary from the very intensive case-management programmes targeted at the very high-risk groups to lower-intensity self-management support programmes targeted at the low-to medium-risk groups. It is important that the intensity of the intervention is appropriate to the level of risk, because the upstream costs should be offset by the downstream care that is avoided (Hutt *et al* 2004).

Case management

Case management is a widely used approach in primary and community care, and is usually a package of home-based care with the broad aim of developing 'cost effective and efficient ways of coordinating services in order to improve the quality of life' (Hutt and Rosen 2005). One format that is beginning to emerge throughout England is the 'virtual ward' – a programme of case management that uses information from predictive modelling tools to target interventions. These are most often built around the GP practice and the patients registered within them.

Evidence is mixed as to whether case management is an effective approach to long-term conditions management. A Department of Health report in 2004 found that one such model, in the United States, had achieved a 50 per cent reduction in unplanned admissions (Department of Health 2004). Similarly, an article in the *British Medical Journal* drawing on observations from the United States concluded that case management is 'very cost effective' (Lewis *et al* 2004).

However, other papers have found that the Kaiser Permanente integration model and Pfizer Health Solutions – both of which include elements of upstream case management – have lower bed usage than the NHS. However, Ham *et al* highlight that the factors contributing to that low bed use tend to be very closely linked to the structural, organisational and financial context that is specific to certain parts of the US system (Ham *et al* 2003).

Further studies have also been equivocal as to the effectiveness of case management. A paper that examined the evidence from 19 studies of case management targeted at older people found only weak evidence that this approach reduced hospital admissions (Hutt *et al* 2004). In addition, the evaluation of Evercare – the US case management programme for older people – found that the programme had no significant impact on emergency admissions (Boaden *et al* 2006).

A systematic review commissioned by Birmingham and Black Country Strategic Health Authority in 2006 found a mix of evidence, with some studies concluding that case management has potential to reduce admissions and length of stay while others found that it had no effect (Ham 2006). Similarly, a more recent paper, which reviewed 10 papers focusing on case management, concluded that there was inconclusive evidence about the effectiveness of case management (Offredy *et al* 2009).

Population-based management in England: six case studies

The current policy of GP commissioning for the NHS in England implies that, as members of commissioning organisations responsible for meeting the needs of local communities cost-effectively, the general practices of the future will become population oriented. For example, an unpublished survey undertaken by The King's Fund suggested that in spring 2009 at least half of all PCTs were using some sort of predictive modelling tool.

In the disease-specific interviews, we asked GP respondents specific questions about whether their general practices were involved in any programmes that attempted to identify patients at risk of deterioration or unplanned admission to hospital. We also asked them to identify the sorts of interventions being employed as a result. (See Appendix 2, question 7.)

In order to explore the issue of population management more directly, we undertook a purposeful sample of six case sites for further investigation. These case studies (described in Table 3) were known to be proactive in population management, and were selected to identify leading-edge approaches to population-based management in primary care and the role that general practice could, and should, play in delivering that.

Each of the six case sites visited had a slightly different model for population management and organisation of services. None have been fully evaluated, so effectiveness cannot be compared, but some elements that are common to all have emerged. These provide an indication of what might constitute effective population management.

Table 3: Population-based management in six English PCTs

Site	Case-finding technique used	Intervention implemented	Progress
Croydon	Combined predictive model	10 virtual wards across the PCT. Virtual wards mirror hospital ward and aim to target home-based case management at high-risk individuals. Each ward run by community matron	Model in place since 2004. Wards rolled out from 2005
Devon	Combined predictive model	Piloting one virtual ward for population of 18,000. GP leading development	Model in place since April 2009. In early stages of setting up ward
Lambeth	Combined predictive model	None. Model outputs being used to identify clinical variation between practices. Practices are told where there are gaps and it is up to them how they close them. PCT led	Model in place since late 2008. Systems and incentives being developed
Norfolk	Combined predictive model	Telephone health coaching for individuals identified as high risk	Coaching ran as pilot for 2 years. PCT no longer funding it
Wandsworth	PARR++ (inpatient data only)	4 virtual wards set up. Each ward has a full-time GP attached to it. GP-led	Model in place since late 2008. Wards developing since early 2009
Nene commissioning (PBC cluster)	None: district nurses and GPs refer to the programme	Proactive Care programme launched – similar to idea of virtual wards	Programme launched in April 2009

Of the six sites, four were pursuing a GP data-based predictive model. However, only one (Croydon) had yet developed a full and centralised system that included electronic GP data from every practice. Of the remaining two sites, one was using a predictive model that uses inpatient data only. The sixth was not using a predictive model, and was relying on clinicians to identify appropriate individuals.

In terms of interventions, all but two of the six case-study sites were in the early stages of implementation. Even the two more developed models (Croydon's virtual wards and Norfolk's telephone health coaching) had not been fully evaluated. However, interviews revealed that the models had three common elements that appeared to be essential to functional population management:

- effective use of available data
- integration and co-ordination across organisational boundaries
- flexibility of, and ability to personalise, services.

Each of these is described below.

Effective use of data

As suggested by the evidence, effective use of available data was key in all the case-study sites. All sites were extracting, sharing and analysing data. Interviewees stressed the importance of using data to understand their population needs. In an ideal world, that GP data would be integrated into the model. Five of the six sites had implemented predictive models – four in order to identify patients suitable for an intervention, and one to identify gaps or variations in clinical care. All interviewees stressed the need to understand their population before embarking on any sort of proactive care.

Nene Commissioning, a practice-based commissioning consortium, was the only site not to have adopted a particular model or approach to case finding. Instead, it had been allowing community matrons, district nurses and GPs to refer into the intervention based on their opinion of the likely risk of the individual. Evidence suggests that this approach is not particularly accurate in identifying the correct individuals in advance, and the group's management team commented that it was considering adopting a more systematic approach.

Interviewees highlighted the advantages of using predictive tools, and the risks of not doing so. One GP, in Devon, said that although GPs get to know certain patients over time, these are not necessarily the patients who will be at risk in future, and so are not necessarily the ones who should be targeted. He explained:

They access more care, you get more paperwork back from the hospital, you're more aware of them, you think they're going into hospital more, you're seeing [them] more, and so they naturally come up your awareness.

GP, Devon

There is then a risk that other patients who are not regularly accessing care may be neglected by the GP – and that these may be the patients whose

risk of admission is rising, and who should be enrolled in a preventive intervention. The GP in question referred to this situation as 'a kind of inverse care law'. In his opinion, using a predictive model ensures 'a level playing field for everyone'.

Some interviewees had been surprised by which patients had been identified as high risk, underlining the importance of using data to assess need. One community matron said:

At the outset of the project, we assumed the most complex patients would be the oldest and frailest, but what we found was that a large number of these people had drug and alcohol problems and mental health problems. So we rapidly had to re-skill our community matrons ... They all had physical conditions as well, but the critical factors around risk were those two.

Community matron, Devon

Interviewees also talked about how linking different datasets can provide an insight into individual needs and can aid decision-making about appropriate care, acknowledging that not all patients can be cared for outside hospital:

It's about saying there are people who can be managed in hospital and people who can be managed in the community – how are we going to have systems in place that either stop that happening or, if they do pitch up at hospital, [ensure that] they get out into the community with the right support?

Manager, Nene

Several sites had experienced difficulties in implementing predictive risk models and new models of preventive care. Many spoke of data issues, including the complexities of extracting data from various different GP systems, the absence of data-sharing agreements and, in some areas, an initial lack of interest among other GPs and/or the PCT. Many mentioned the varying levels of enthusiasm for the approach among GPs, and stressed the importance of engaging with GPs and persuading them to see the power of sharing and using data.

Integration and co-ordination

All but one of the case-study sites saw integration of general practice with other care services as a key element of proactive LTC management. Many felt that at present there was confusion among GPs about service availability, with patients falling through gaps as a result of poor continuity of care. As a result of these issues, some respondents reported patients ending up in a 'cycle of re-admissions' that undermines their independence and ability to self-manage their conditions:

Rarely do those patients come out from hospital any better than when they went in. The acute phase may be stabilised, but actually their condition is a lot worse, and they have been put through another barrage of tests. They have met a whole new range of doctors who want to use them as pin cushions, and it is awful – really awful.

GP, Croydon

Once they're in [hospital], it's inordinately difficult to then get people back into their own homes because they go off their legs. They lose their independence.

PBC-lead, Nene

Far from calling for major restructuring of general practice, or the creation of new teams or posts, all the interviewees we spoke to felt that the key thing was better co-ordination and integration of existing services. Only one site had actually developed a wholly new service (health coaching). The four that were in the process of implementing virtual wards were largely streamlining access to existing services and co-ordinating care across the professions. One GP explained how GPs had become confused by the array of services available and had endeavoured to set up a system where there was a single point of access to all services:

It's more about processes, really. It's trying to formalise the processes but not over-complicate them... You go from one extreme, where people aren't co-ordinated, and you could have prevented admission or prevented someone maybe [from] ending up in long-term social care. ...[Now], you can just refer to the co-ordinator who then discusses it, gets information, if you think it's a likely crisis then goes to Rapid Response, and ... they can bring it back to court where we can discuss them... Just to make it simpler, really.

GP, Devon

What we want is a model that integrates the community matrons and the GP practices. What the GPs, in particular, didn't want was community matrons going off and doing their own thing in isolation of the practice. It didn't feel like that was a model that was going to work.

PBC lead, Nene

However, others saw the potential of extending the concept of integration beyond primary and community care and into mental health, social care, secondary care and the voluntary sector:

There's a need in primary care certainly to work with secondary care, get rid of those... very artificial boundaries, and actually say 'OK, who's going to do what at each step of this person's journey?' There are loads of people out there that could actually do more, but we're very ringfenced in terms of who does what and how it all works.

Community matron, Croydon

Others felt that the integration and co-ordination had to be even wider, and talked of a whole-systems approach to proactive care:

I think we have to have a whole-systems approach. I don't think community matrons on their own will make that much difference. I think the whole-system approach is where you'll get big swings.

Director of Nursing, Croydon

Certainly, existing evidence would support the move away from single disease-focused initiatives. A high proportion of individuals at high risk of admission have multiple conditions, and many of these individuals have mental health needs (Billings *et al* 2006a).

Personalisation and flexibility

The third key element was the ability to use services flexibly to enable personalisation. Although there might be scope to segment a population into risk groups, individuals within each group are likely to have very different needs. In all five patient-focused models there was a strong emphasis on care planning and needs assessment. Interviewees stressed the importance of being able to put together a personalised care package, drawing on different expertise as and when required.

A key enabler of this was the existence of a central contact point for patients. Patients were given a named care manager to look after their care package and co-ordinate their care. Since many people with long-term conditions do not need specialist clinical input, the approach was considered appropriate in enabling patients to self-manage their own conditions. In order to build this confidence, the care managers or co-ordinators in the case-study sites reported spending considerably more time with patients than GPs and nurses in practices would normally have had available. As one GP put it:

A big selling point for the GP [is that] actually it makes things a bit easier. If you've got complex patients who are higher up the list, they tend to have more appointments, they tend to ring you up more because they're unsure, and you end with more visits... So the idea is, a lot of this is burden, in a way. It's not totally transferred on to the team or the matron, but they have more time to deal with it. So that's where you get things like health coaching and expert patients, because community matrons have more time to discuss their needs with them, break down what's going on and actually change behaviours. And I think it's the changing behaviours that takes time.

GP, Devon

What is the role of general practice?

Although in all six case studies general practice clearly plays a key role, what is also clear is that in most cases, the models have actually enabled GPs to step away from the hands-on care of these patients and for the care co-ordinators to provide that input. GPs have tended to take on a more peripheral, advisory role where they are still responsible for their patients' clinical well-being, and where they input into care planning and provide care when required, but they are freed up to focus on other patients.

Out of the six case studies we investigated, only two placed GPs at the centre of the service.

- **The Wandsworth model** The PCT is running the predictive model centrally but then sending the outputs to four GPs, who are employed to work on the virtual ward full time. GPs then assess the model outputs and undertake assessments of those patients who are identified, in order to put together a package of care. This model is similar to other virtual ward models except that the care co-ordinator is a GP rather than a community matron or nurse.
- **The Lambeth model** The PCT is running the predictive model centrally and sending results to PBC cluster managers. Those managers are then using the outputs to identify clinical gaps, and

targets for closing those gaps are agreed with the PCT. It is then up to the individual GPs or practices to decide how to close those gaps.

The other case studies all involve GPs to some extent, but it was the importance of the general practice as the organising unit that appeared to be crucial, rather than the GPs themselves undertaking the activities. Other than in the Norfolk telephone health coaching, which was run by the PCT with very little direct input from general practice, GPs remained responsible for the clinical well-being of their patients, while the operational and co-ordination side was run by community matrons or nurses.

In the four virtual ward examples, the GP role involves the following.

- **Being the central unit of organisation** For example, virtual wards are organised around catchment areas of practices. This gives the intervention a geographical limit, for planning purposes, and longitudinal data can be gained on the registered list of patients enrolled with them.
- **Playing a leadership role** Under PBC, and now under GP commissioning, GPs need to lead the implementation of proactive care and the system that are required to support it. GPs play an increasingly important role in bringing together the different professions and services to provide proactive care.
- **Being a source of data and sharing that data** The data must be shared with other practices and the PCT in order for it to be used in a predictive model.
- **Championing predictive models** This involves championing and encouraging use of evidence-based predictive models.
- **Analysing outputs** The GP must analyse (or jointly analyse, with the care co-ordinator) outputs from the model in order to identify any patients unsuitable for the intervention and agreeing a case list. (For example, in some sites this might involve excluding young people with mental health problems who are known to the specialist service.) He or she must also analyse population data, to identify emerging and unmet need and act on this information.
- **Linking in with services** The GP must play a leadership role in mapping out what services are available and forging links and partnerships across organisational boundaries.
- **Having clinical input into the care plan of an individual** This might involve visiting the individual, but would usually involve discussing the case with the care co-ordinator and advising on clinical aspects of their care. Some of the role might involve outreach to patients who do not often come forward for care.
- **Maintaining an overview of their patient's well-being** This involves regularly liaising with the care co-ordinator while delegating the day-to-day management of patients to the care co-ordinator. It also involves empowering care co-ordinators to make informed decisions.
- **Being part of a multi-disciplinary team** The GP will attend regular meetings or 'ward rounds' where patients on the 'ward' are discussed and the level of care required decided.

- **Clinical responsibility** The GP maintains responsibility for the clinical well-being of their patients.
- **Playing an evaluative and quality assurance role** This is intended to make sure that the intervention is delivering appropriate care and has the intended impact. This might be carried out in partnership with the PCT, but it seems to be important that the GP recognises the importance of evaluation and participates fully. Under GP commissioning, this role will become even more important.

Of all of these tasks, what appears to be most critical to a proactive population-based intervention is not a fundamental change in the infrastructure of general practice and its model of practice. It is a shift in attitudes and culture – from one where the GP is the sole reactive caregiver to one where the GP takes on a more expert advisory role. This advisory role involves working closely with other professions, to help offer the patient a co-ordinated, seamless package of care. GP engagement and involvement is important to the development of the service. In most examples, GPs have played a key role in brokering and building relationships across organisational divides.

Of course, the structure of proactive models will vary according to a number of factors – one of which will be the size and structure of the practice. Our case studies did not seek to draw conclusions about such factors, but it is likely that small and single-handed practices might not have capacity to deliver such care alone, so the idea of co-ordination, integration and networks of care will become even more critical.

Evidence suggests there is potential in population management for improving care quality to patients with long-term care needs, and there is some potential that the approach can lead to cost savings when targeted at the right people. As GP commissioning takes over from PCT-led commissioning, reducing unscheduled hospital and care-home admissions will become a key priority for general practice, and its partners and population management will become an essential tool in achieving cost reductions without compromising on care quality. The high-quality general practice of the future will be judged as much for its role and contribution in managing population health cost-effectively and proactively as it will on the care and services it traditionally provides to patients.

9 Conclusions

The aim of this study was to attempt to establish what best practice in long-term conditions management should look like, the role of general practice in delivering high-quality care, and the generic measures that might be used by those in general practice to enable quality improvement.

This research has revealed that there is a significant amount of guidance and expert agreement on what should constitute high-quality care across the dimensions of LTC care examined. However, there is relatively little agreement on what role general practice should play with other partners in the health and social care system to deliver it. Moreover, apart from certain clinical indicators included in the QOF, there is very little data and information available to make a comparative judgement of the current quality of LTC care – whether in general practice, or between general practice and its key partners.

What the evidence suggests is that improvements have indeed been made over the years – particularly in diabetes. There are also indications that the QOF has contributed to practices giving more attention to the ongoing management of patients with diabetes and other chronic illnesses such as heart disease and COPD.

However, the evidence also suggests that care quality is currently sub-optimal and highly variable, and could be significantly improved through a better understanding of long-term conditions among primary care professionals and a more proactive approach to care management. What is clear is that responsibility for delivering high-quality care to patients should be shared across care settings and multi-professional teams, and that general practice has a core role to play as part of that continuum of care. The overall picture, therefore, appears to be one of improvement, but also of a lost opportunity to redesign primary and community care to better meet the needs of those with long-term chronic care needs – for example, in the ways described by the NSF for long-term conditions (Department of Health 2005a).

Measuring quality

It is clear that many of the dimensions of quality that could be used for promoting LTC management in general practice are hard to measure, and do not lend themselves readily for development into an objective measure or indicator. This is not least because the data and information required to collect such information is currently not available within general practice or other datasets (or, if it is available, it is not currently used). It would need to be collected through bespoke local audits, patient surveys and/or the development of specific measurement tools.

However, we believe that measures of quality need to be developed to support general practice (in partnership with its health and social colleagues) to improve the quality and cost-effectiveness of care to people living with long-term conditions. This should be seen as a policy priority – the NHS is long past the tipping point where the option of not redesigning care to meet the needs of those with complex chronic illnesses is tenable, and the

development and use of credible quality markers would almost certainly be an asset for use as a tool for change.

We have, therefore, given some thought to the various generic dimensions of quality in LTC management and care that are important in general practice. These are presented below, together with an assessment as to whether general practice as a whole is active in these areas.

- **Evidence of practice registries** Practice registries for patients with long-term conditions needs to be established in general practice, to support the management of all patients with chronic illness. This has improved across all general practice in recent years as a result of QOF incentives. However, not all LTCs are covered and few practices take an active interest in keeping or updating registries for other conditions – especially to those with multiple care needs.
- **Evidence for proactive case finding** Proactive case finding across practice populations, through regular analysis of data with community nurses and other partners, appears important in enabling a better multi-professional understanding of practice populations and so helps to target services at individuals in needs of care. The evidence suggests that currently very few general practices are proactive in this area, and that many have not been willing to contribute practice data and information to support such activities. Even in 'go-ahead' sites, the evidence suggests that GPs have taken a peripheral interest, leaving the work to community matrons and others.
- **Availability of practice-level data** Practices should make practice-level information and data at the practice level available. This is because evidence of practices' ability to extract high-quality patient data, and to share that data with other care providers regularly, is a prerequisite to effective population management.
- **Problem recognition, early diagnosis and appropriate swift referral for an early intervention** Problem recognition, early diagnosis and swift referral generally result in the better management of people with LTCs. However, it is clear that problem recognition among many GPs can be highly variable. For example, the evidence on care for people with arthritis, dementia and depression suggests that many GPs and nurses in general practice may need further education and training in order to identify symptoms and to ensure prompt referrals to appropriate follow-on care.

The evidence also indicates a significant challenge in the lack of specialist support for many GPs, compounded by a lack of time during the consultation in making an effective diagnosis. Hence, general practice faces a number of barriers in diagnosing diseases – especially those such as dementia. GPs will not necessarily encounter a high number of cases of people presenting with early signs of these complex illnesses. Combined with a lack of specific skills and training, this can make it difficult for them to identify potential cases.

For patients presenting with symptoms requiring specialist diagnosis and/or treatment, a regular audit of practice-level records (for example, to ascertain whether timeliness of referrals was meeting NICE or other treatment guidelines) could be one approach to examining care quality in this area.

- **Patient information** Providing patients with information about their LTCs can be effective in helping them self-manage and/or prevent deterioration in illness. This is a common element in most NICE guidance. However, the quality of information provision is currently variable. One way to ensure this was being routinely undertaken would be to examine patient records to assess the percentage of patients with symptoms of LTCs whose notes state that written information was provided.
- **Supported self-care** General practice should provide supported self-care, such as remote monitoring of the patient's condition or enrolling them in an education or peer support group. They should also help to provide or signpost patients to receive this, since there is strong evidence to suggest that this approach can improve outcomes – particularly for people with multiple LTCs.
- **Support for carers** Providing support for carers is particularly important. General practices, with their key care partners, should be tasked with ensuring that carers are also offered access to education and support.
- **Regular follow-up appointments** Another core component of good LTC management is a system of regular follow-up appointments, ensured through an organised process. Some QOF measures pick this up, though generally only for a single follow-up. Evidence suggests that regular follow-ups to those who need them is variable. General practice needs to ensure that it monitors the percentage of patients who meet the criteria for follow-up appointments who are actually offered and receive one.
- **Patient-centred care plans** It has been a policy commitment since 2006 that all LTC patients should have patient-centred care plans written for them. QOF (MH06) measures this for patients with psychosis. To encourage proactive care planning and follow-up, such care planning needs to be a feature of all those with a limiting long-term condition. The patient records within general practice should ensure that these are recorded as having been provided, and by whom.
- **Multi-disciplinary care planning** The care-planning process needs to be multi-disciplinary in order to identify issues to do with the 'whole person', including the presence of other long-term illnesses or social care needs. This is important, since evidence suggests that patients with LTCs often have more than one LTC and so have needs that span care sectors. One way to establish whether this was being undertaken would be to set up a system of noting in a patient's care record that a care plan has been developed and provided to patients, with appropriate input from professionals outside of general practice. Another method of assessment might be feedback from patients (for example, on whether they received, contributed and understood the care plan).
- **The planning process as a single point of entry** Using the planning process as a single point of entry to a range of services would help patients receive a more integrated service. This might require general practice to ensure that patients are receiving the support of a

designated care co-ordinator to help case manage their illness, even if general practice itself does not undertake the co-ordination role.

- **Case management** One measure for whether the planning process is used as a single point of entry might be to record the percentage of patients meeting criteria who are offered or provided with case management. This is because evidence suggests that targeted case management can improve outcomes for some people with LTCs.
- **Multi-disciplinary working** Working in a multi-disciplinary team is important in many aspects of care delivery for those with LTCs – for example, in having a single or co-ordinated assessment process or care plan (see above), or in screening those with physical and mental health care needs. People with physical co-morbidity have a high prevalence of depression. At present, this can result in poorer quality of care and outcomes than might be the case through closer partnership working.
- **Patient satisfaction** The quality of patient care is often considered less good for people with multiple LTCs, so practices should measure patient satisfaction among those patients. Practice-level surveys, undertaken as part of GP contract requirements, could be cross-referenced with patient histories to examine the experiences of these groups of patients. This is important, since there is some evidence to suggest that patients who come away from consultations feeling more empowered and informed about their illness are less likely to require formal care in the future.
- **Outcome measures** It is useful to track outcome measures such as patient experiences (for example, on quality of life or social inclusion), clinical outcomes and/or emergency hospital admissions and lengths of stay, since key outcomes measures of interventions would be whether these have improved. It would be particularly informative to be able to compare outcomes for people with multiple long-term conditions with those with a single disease.

This long list of quality markers above should be treated with great caution. It is not intended to represent a set of measures or indicators that could be used to hold general practice (or any other provider) to account. Instead, the markers should be seen as the key domains through which the quality of LTC management could be examined in a general practice context.

What is more, the list is not exhaustive, since our research picked up on other quality issues (including the quality of doctor–patient relationships, equity of treatment, and care continuity) that have been addressed in more detail in other report in the GP Inquiry series (see Freeman and Hughes 2010; Greenhalgh and Heath 2010; Hutt and Gilmour 2010).

However, what the list does presuppose is that general practice cannot be expected (or, indeed, allowed) to deliver high-quality care to those with LTCs without good systems of integrated care working with other care providers – an overarching systemic problem that this research has uncovered, and one that needs urgent attention.

The future role of general practice in meeting the challenge

There are a number of challenges for general practice if they are to deliver a higher quality of care to people with long-term chronic illnesses. These challenges refer to two main issues: the current knowledge and skills levels within general practice, and the way in which general practice is configured, since the care planning and care co-ordination processes imply the need for integrated care with other services and professionals.

The current knowledge and skill levels within general practice

One of the most pressing issues raised by the evidence is the ability for an early diagnosis of LTC patients to be undertaken in general practice settings, and/or for a referral to be made that leads to an appropriate and early intervention from a specialist.

As generalists, it is understandable that GPs and practice nurses do not necessarily have extensive or detailed knowledge of every LTC and how these should be managed. Yet there must be access to accredited and standardised training in LTC management in general practice and/or systems that enable nurses and GPs to refer patients to a local specialist team for advice and care where needed. This professional development of staff employed in general practice is vital, given that the management of long-term conditions is being pushed further into the community.

It is fair to say that a very high level of input would be needed from GPs, practice nurses and other general practice staff to deliver all the different aspects of high-quality care for the range of long-term conditions that need to be managed. Meeting the LTC agenda places a strain on their ability to manage the needs of complex patients, since they require trade-offs in the time they might otherwise have for other patients. Put simply, there is a lot for GPs or nurses to cover in a single 10- or 15-minute appointment. This increases the likelihood of some aspects of care being overlooked – particularly those requiring more in-depth discussion, such as for care planning for those with multiple LTCs and associated depression.

Gaps in knowledge and skills also apply to GPs' and nurses' abilities in the care-planning process, since their role in acting as patient guide and advocate to access the multiple providers of the care they might need is not sufficiently embedded in the culture of general practice. Care-planning skills must be included in the professional development of GPs and practice nurses in the future, so that they are able to:

- produce the care plan collaboratively
- review the care plan regularly
- handle the situation of patients not meeting their goals sensitively and constructively
- provide praise and motivation to the patient when they have achieved their goals.

There are other barriers that are more personal to GPs and practice nurses, such as attitudes and beliefs. For example, one survey estimated that only 60 per cent of GPs believed it was important to look for early signs of dementia, with only half of the sample believing that 'much can be done to improve

the quality of life for people with dementia' (NAO 2007, p 27). Many of the experts we interviewed suggested that GPs and nurses in general practice are often unaware of the various services and resources in the community and voluntary sector from which patients with LTCs could benefit.

Given the expectation that general practice should take on responsibility for providing high-quality care to patients with long-term conditions, this range of structural and workforce challenges needs urgent attention. A substantial amount of community-based care will need to be taken on in an attempt to shift care out of hospitals and nursing homes and into the primary care or home environment.

How general practice is configured

The workload and workforce implications in managing people with LTCs are profound. Most general practices are not in a position to deal with such demand adequately, unless they are well networked with other practices and the rest of the system. There are some potential skill-mix solutions to this situation that could be employed. One example would be to develop longer, group consultations to talk to, say, six patients or more about – for example – diabetes and/or anxiety management. Meanwhile, health care assistants could take responsibility for monitoring patients' blood pressure and weight, providing written information or signposting to sources of information if appropriate.

The most significant issue for general practice in meeting the LTC challenges will be to embrace specialist support during the consultation process, during care planning, and in ongoing care in a way that makes patients feel like equal partners in their care, better supporting them to manage their own illness. However, a two-fold problem exists:

- the lack of time, skills and capacity in general practice to make an effective diagnosis for all people with LTCs
- the lack of communication with (and availability of) specialist services.

Budget constraints also impede the commissioning of self-management sessions, physiotherapy or physical exercise sessions.

It is unlikely that these challenges can be met without more fundamental structural changes to the way general practice operates. The shift to larger group practices, polyclinics and those working in 'federations' of practices has already begun. However, general practice needs to become more closely integrated with the care and delivery of other providers and, potentially, seek to develop 'integrated care organisations' that overcome the NHS design flaw of the separation between primary, community and hospital care (Lewis *et al* 2010).

Such structural changes to the nature of general practice would be controversial because they present a different future for GPs and their specialist colleagues. However, given the needs of population management, rooting such organisations around general practice and the registered list would appear to be the most logical way forward, since it comes closest to the image of an organisation that could effectively co-ordinate the care for people with LTCs across multiple care services.

The coalition government's plans for GP commissioning would suggest a move towards creating a more population-based focus to the role of general practice, as it becomes responsible for the health and welfare of communities in addition to their traditional responsibilities to enrolled patients. Even so, general practice would have a significant distance to travel to fulfil the vision, since the managerial capacity of a small business will be wholly unable to meet the challenge. For many GPs, integrated care will be a step too far and they will remain content to offer face-to-face clinical services.

Achieving higher quality care to people with LTCs requires the evolution of multi-specialty local clinical partnerships and a shared care model of working – as examined in a recent Nuffield Trust/NHS Alliance report (Smith *et al* 2009). In this way general practice might find its way to becoming a full partner in what might be called population-oriented primary care.

References

Aliotta SL, Grieve K, Giddens JF, Dunbar L, Groves C, Frey K, Boulton C (2008). 'Guided care: a new frontier for adults with chronic conditions'. *Prof Case Manag* 13 (3): 151–58.

Alzheimer's Society (2010). *Updated Estimates on the Numbers of People With Dementia in the UK Based on Data in the Dementia UK Report*. Briefing paper. London: Alzheimer's Society.

Alzheimer's Society (2007). *Dementia UK. The full report*. London: Alzheimer's Society. Available at: www.alzheimers.org.uk/downloads/Dementia_UK_Full_Report.pdf (accessed on 26 August 2009).

Arthritis and Musculoskeletal Alliance (2009). *Joint Working? An audit of the implementation of the Department of Health's musculoskeletal services framework*. London: ARMA. Available at: www.arma.uk.net/policy.html (accessed on 5 November 2009).

Arthritis and Musculoskeletal Alliance (2004a). *Standards of Care for People with Inflammatory Arthritis*. London: ARMA. Available at: www.arma.uk.net/pdfs/ia06.pdf (accessed on 23 June 2009).

Arthritis and Musculoskeletal Alliance (2004b). *Standards of Care for People with Osteoarthritis*. London: ARMA. Available at: www.arma.uk.net/pdfs/oa06.pdf (accessed on 23 June 2009).

Arthritis Care (2008). *Living with Rheumatoid Arthritis*. London: Arthritis Care. Available at: www.arthritiscare.org.uk/AboutArthritis/Conditions/Rheumatoidarthritis (accessed on 23 June 2009).

Arthritis Care (2007). *The Impact of Arthritis (statistics)*. Factsheet. London: Arthritis Care. Available at: www.arthritiscare.org.uk/PublicationsandResources/Arthritisbasics/Arthritisstatistics (accessed on 23 June 2009).

Arthritis Research UK (2008). *Arthritis in the UK – Key facts*. Chesterfield: Arthritis Research UK. Available at: www.arthritisresearchuk.org/pdf/Arthritis%20Key%20Facts.pdf (accessed on 23 June 2009).

Arthritis Research Campaign (2002). *Arthritis. The big picture*. Derbyshire: ARC.

Audit Commission (2002). *Forget Me Not. Developing mental health services for older people in England*. London: Audit Commission. Available at: www.audit-commission.gov.uk/nationalstudies/health/mentalhealth/pages/forgetmenot.aspx#downloads (accessed on 26 August 2009).

Bachman J, Swenson S, Reardon ME, Miller D (2006). 'Patient self-management in the primary care treatment of depression'. *Adm Policy Ment Health* 33 (1): 76–85.

Banerjee S, Willis R, Matthews D, Contell F, Chan J, Murray J (2007). 'Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model'. *International Journal of Geriatric Psychiatry* 22 (8): 782–88.

Banerjee S, Wittenberg R (2009). 'Clinical and cost-effectiveness of services for early diagnosis and intervention in dementia'. *International Journal of Geriatric Psychiatry* 24 (7): 748–54.

Barbui C, Tansella M (2006). 'Identification and management of depression in primary care settings. A meta-review of evidence'. *Epidemiol Psichiatr Soc* 15 (4): 276–83.

Belnap B, Kuebler J, Upshur C, Kerber K, Mockrin DR, Kilbourne AM, Rollman BL (2006). 'Challenges of implementing depression care management in the primary care setting'. *Adm Policy Ment Health* 33(1): 65–75.

Billings J, Mijanovich T (2007). 'Improving the management of care for high-cost Medicaid patients'. *Health Affairs* 26 (6): 1643–54.

Billings J, Mijanovich T, Dixon J, Curry N, Wennberg D, Darin B, Steinort K (2006a). *Case Finding Algorithms For Patients at Risk of Re-hospitalisation PARR1 and PARR2*. London: The King's Fund. Available at: www.kingsfund.org.uk/current_projects/predicting_and_reducing_readmission_to_hospital/#resources (accessed on 10 July 2010).

Billings J, Dixon J, Mijanovich T, Wennberg D (2006b). 'Case finding for patients at risk of readmission to hospital: development of algorithm to identify high risk patients'. *British Medical Journal* 333: 327.

Billings J, Mijanovich T, Dixon J, Williams M, Curry N, Wennberg D, Hall C, Darin B (2005). *Case Finding Algorithm for Patients at Risk of Hospitalisation*. London: The King's Fund.

Billings J, Zeitel L, Lukomnik J, Carey TS, Blank AE, Newman L (1993). 'Datawatch: impact of socioeconomic status on hospital use in New York City'. *Health Affairs (Millwood)* 12 (1): 162–73.

Boaden R, Dusheiko M, Gravelle H, Parker S, Pickard S, Roland M, Sargent P, Sheaff R (2006). *Evercare: Evaluation of the Evercare approach to case management: final report*. University of Manchester: National Primary Care Research and Development Centre.

Boult C, Reider L, Frey K, Leff B, Boyd CM, Wolff JL, Wegener S, Marsteller J, Karm L, Scharfstein D (2008). 'Early effects of "Guided Care" on the quality of health care for multimorbid older persons: a cluster-randomized controlled trial'. *J Gerontol A Biol Sci Med Sci* 63 (3): 321–27.

Boardman J, Walters P (2009). 'Managing depression in primary care: it's not only what you do it's the way that you do it'. *Br J Gen Pract* 59 (559): 76–78.

Bower P, Gilbody S, Richards D, Fletcher J, Sutton A (2006). 'Collaborative care for depression in primary care. Making sense of a complex intervention: systematic review and meta-regression'. *Br J Psychiatry* 189: 484–93.

Boyce T et al (2010). *The Quality of Health Promotion and Ill Health Prevention in General Practice*. The King's Fund: London.

Boyd CM, Boult C, Shadmi E, Leff B, Brager R, Dunbar L, Wolff JL, Wegener S, (2007). 'Guided care for multimorbid older adults'. *Gerontologist* 47 (5): 697–704.

Boyd CM, Darer J, Boult C, Fried LP, Boult L, Wu AW (2005). 'Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases: implications for pay for performance'. *JAMA* 294 (6): 716–24.

Breedveld F (2004). 'Osteoarthritis – the impact of a serious disease'. *Rheumatology*, 43 (suppl 1): i4–i8.

Broadbent J, Maissey S, Holland R, Steel N (2008). 'Recorded quality of primary care for osteoarthritis: an observational study'. *British Journal of General Practice* 58 (557): 839–43.

Brown I, Thompson J, Tod A, Jones G (2006). 'Primary care support for tackling obesity: a qualitative study of the perceptions of obese patients'. *British Journal of General Practice* 56 (530): 666–72.

Callahan CM (2001). 'Quality improvement research on late life depression in primary care'. *Med Care* 39 (8): 772–84.

Calvert M, Shankar A, McManus RJ, Lester H, Freemantle N (2009). 'Effect of the quality and outcomes framework on diabetes care in the United Kingdom: retrospective cohort study'. *BMJ* 338 (262): 1363–72.

Campbell S, Reeves D, Kontopantelis E, Middleton E, Sibbald B, Roland M (2007). 'Quality of primary care in England with the introduction of pay for performance'. *New England Journal of Medicine* 357 (2): 181–90.

Campbell SM, Reeves D, Kontopantelis E, Sibbald B, Roland M (2009). 'Effects of pay for performance on the quality of primary care in England'. *New England Journal of Medicine* 361 (4): 368–78.

Chapman DP, Perry GS, Strine TW (2005). 'The vital link between chronic disease and depressive disorders'. *Prev Chronic Dis* 2 (1): A14.

Comas-Herrera A, Wittenberg R (eds) (2003). *European Study of Long-Term Care Expenditure*. Report to the European Commission, Employment and Social Affairs DG. London: Personal Social Services Research Unit, London School of Economics.

Comas-Herrera A, Wittenberg R, Pickard L, Knapp M (2007). 'Cognitive impairment in older people: future demand for long-term care services and associated costs'. *International Journal of Geriatric Psychiatry* 22 (10): 1037–45.

Cousins MS, Shickle LM, Bander JA (2002). 'Introduction to predictive modelling'. *Disease Management* 5 (3): 157–167.

Cowie L, Morgan M, White P, Gulliford M (2009). 'Experience of continuity of care of patients with multiple long-term conditions in England'. *J Health Serv Res Policy* 14 (2): 82–87.

Croghan TW, Schoenbaum M, Sherbourne CD, Koegel P (2006). 'A framework to improve the quality of treatment for depression in primary care'. *Psychiatr Serv* 57 (5): 623–30.

Curry N, Billings J, Darin B, Dixon J, Williams M, Wennberg D (2005). *Predictive Risk Project: Literature review*. The King's Fund: London.

Darzi A (2008). *High Quality Care for All: NHS next stage review final report*. London: Department of Health.

Department of Health (2010). *Equity and Excellence: Liberating the NHS*. London: Department of Health.

Department of Health (2009a). *Your Health, Your Way: A guide to long-term conditions and self care*. London: Department of Health

Department of Health (2009b). *Personal Health Budgets: First steps*. London: Department of Health.

Department of Health (2009c). 'Integrated care pilots'. Department of Health website. Available at: <http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/IntegratedCare/Integratedcarepilots/index.htm> (accessed on 10 August 2010).

Department of Health (2009d). *Living Well with Dementia. A national dementia strategy*. London: Department of Health.

Department of Health (2007a). 'Case management'. Department of Health website. Available at: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/Longtermconditions/DH_4130655 (accessed on 10 August 2010).

Department of Health (2007b). *World Class Commissioning: Vision*. London: Department of Health.

Department of Health (2007). 'The Expert Patients Programme'. Department of Health website. Available at: www.dh.gov.uk/en/Aboutus/MinistersandDepartmentLeaders/ChiefMedicalOfficer/ProgressOnPolicy/ProgressBrowsableDocument/DH_4102757 (accessed on 10 September 2009).

Department of Health (2007a). *Making Every Young Person with Diabetes Matter*. Department of Health website. Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073674 (accessed on 10 August 2009).

Department of Health (2007b). *Who Gets Diabetes – Health inequalities*. London: Department of Health. Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4899972 (accessed on 10 August 2009).

Department of Health (2006a). *Diabetes Commissioning Toolkit*. London: Department of Health. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4140285.pdf (accessed on 9 April 2010).

Department of Health (2006b). *Our Health, Our Care, Our Say: A new direction for community services*. London: Department of Health.

Department of Health (2006c). *The Musculoskeletal Services Framework*. London: Department of Health. Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138413 (accessed on 22 June 2009).

Department of Health (2005a). *Supporting People with Long-Term Conditions*. London: Department of Health.

Department of Health (2005b). *The National Service Framework for Long-Term Conditions*. London: Department of Health.

Department of Health (2004a). *Chronic Disease Management – A compendium of information*. London: Department of Health.

Department of Health (2004b). *The NHS Improvement Plan: Putting people at the heart of public services*. London: Department of Health.

Department of Health (2003). *National Service Framework for Diabetes: Delivery strategy*. London: Department of Health.

Department of Health (2002). *National Service Framework for Diabetes: Standards*. London: Department of Health.

Department of Health (2001). *National Service Framework for Older People*. London: Department of Health. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4071283.pdf (accessed on 26 August 2009).

Diabetes UK (2010). 'Causes and risk factors'. Diabetes UK website. Available at: www.diabetes.org.uk/Guide-to-diabetes/Introduction-to-diabetes/Causes_and_Risk_Factors/ (accessed on 20 April 2010).

Diabetes UK (2009). *Diabetes UK Survey of People with Diabetes and Access to Healthcare Services 2009*. London: Diabetes UK. Available at: www.diabetes.org.uk/Professionals/Publications-reports-and-resources/Reports-statistics-and-case-studies/Reports/At-a-glance-Diabetes-UK-Survey-of-People-with-Diabetes-and-Access-to-Healthcare-Services-2009 (accessed on 14 April 2010).

Diabetes UK (2008). *The National Service Framework (NSF) for Diabetes. Five years on... are we half way there?* London: Diabetes UK. Available at: www.diabetes.org.uk/Documents/Reports/Five_years_on_-_are_we_half_way_there2008.pdf (accessed on 10 August 2009).

Diabetes UK/Health Foundation/NHS National Diabetes Support Team (2008). *Getting to Grips with the Year of Care: A practical guide*. London: Diabetes UK. Available at: www.diabetes.org.uk/Professionals/Service-improvement/Year-of-Care/The-Year-of-Care-concept/Year-of-Care---care-planning/ (accessed on 13 April 2010).

Dixon J, Lewis R, Rosen R, Finlayson B, Gray D (2004). *Managing Chronic Disease: What can we learn from the US experience?*. London: The King's Fund.

Downs M, Turner S, Bryans M, Wilcock J, Keady J, Levin E, O'Carroll R, Howie K, Iliffe S (2006). 'Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study'. *BMJ* 332:692

Dowrick C (2009). 'Depression: beyond the disease era'. *London Journal of Primary Care* 2: 24–27.

Emery P, Breedveld FC, Dougados M, Kalden JR, Schiff MH, Smolen JS (2002). 'Early referral recommendation for newly diagnosed rheumatoid arthritis: evidence based development of a clinical guide'. *Annals of Rheumatic Diseases* 61: 290–97.

Emery P (2006). 'Clinical review: treatment of rheumatoid arthritis'. *BMJ* 332: 152–55.

Evans DL, Charney DS, Lewis L, Golden RN, Gorman JM, Krishnan KR, Nemeroff CB, Bremner JD, Carney RM, Coyne JC, Delong MR, Frasurre-Smith N, Glassman AH, Gold PW, Grant I, Gwyther L, Ironson G, Johnson RL, Kanner AM, Katon WJ, Kaufmann PG, Keefe FJ, Ketter T, Laughren TP, Leserman J, Lyketsos CG, McDonald WM, McEwen BS, Miller AH, Musselman D, O'Connor C, Petitto JM, Pollock BG, Robinson RG, Roose SP, Rowland J, Sheline Y, Sheps DS, Simon G, Spiegel D, Stunkard A, Sunderland T, Tibbits P Jr, Valvo WJ (2005). 'Mood disorders in the medically ill: scientific review and recommendations'. *Biol Psychiatry* 58 (3): 175–89.

- Ford DE (2006). 'Primary care physician perspective on management of patients with depression'. *J Manag Care Pharm* 12 (2): 10–13.
- Fortin M, Bravo G, Hudon C, Vanasse A, Lapointe L (2005a). 'Prevalence of multimorbidity among adults seen in family practice'. *Ann Fam Med* 3 (3): 223–28.
- Fortin M, Lapointe L, Hudon C, Vanasse A (2005b). 'Multimorbidity is common to family practice: is it commonly researched?'. *Can Fam Physician* 51: 244–45.
- Fortin M, Soubhi H, Hudon C, Bayliss EA, Akker M v d (2007). 'Multimorbidity's many challenges'. *BMJ* 334 (7602): 1016–17.
- Gardner SG, Bingley PJ, Sawtell PA, Weeks S, Gale EAM (1997). 'Rising incidence of insulin dependent diabetes in children aged under 5 years in the Oxford region: time trend analysis'. *BMJ* 315: 713–17.
- Gilbody S, Whitty P, Grimshaw J, Thomas R (2003). 'Educational and organizational interventions to improve the management of depression in primary care: a systematic review'. *JAMA* 289 (23): 3145–51.
- Gilbody S, Bower P, Whitty P (2006). 'Costs and consequences of enhanced primary care for depression: systematic review of randomised economic evaluations'. *Br J Psychiatry* 189: 297–308.
- Gillies CL, Lambert PC, Abrams KR, Sutton AJ, Cooper NJ, Hsu RT, Davies MJ, Khunti K (2008). 'Different strategies for screening and prevention of type 2 diabetes in adults: cost effectiveness analysis'. *BMJ* 336 (7654): 1180–85.
- Gilmore KA, Hargie O (2000). 'Quality issues in the treatment of depression in general practice'. *Int J Health Care Qual Assur Inc Leadersh Health Serv* 13 (1): 34–41.
- Goyder E, Wild S, Fischbacher C, Carlisle J and Peters J (2008). 'Evaluating the impact of a national pilot screening programme for type 2 diabetes in deprived areas of England'. *Family Practice* 25 (5): 370–75.
- Gravelle H, Dusheiko M, Sheaff R, Sargent P, Boaden R, Pickard S, Parker S, Roland M (2006). 'Impact of case management (Evercare) on frail elderly patients: controlled before and after analysis of quantitative outcome data'. *British Medical Journal* 334: 31.
- Gray J, Millett C, Saxena S, Netuveli G, Khunti K, Majeed A (2007). 'Ethnicity and quality of diabetes care in a health system with universal coverage: population-based cross-sectional survey in primary care'. *Journal of General Internal Medicine* 22: 1317–20.
- Greaves CJ, Middlebrooke A, O'Loughlin L, Holland S, Piper J, Steele A, Gale T, Hammerton F and Daly M (2008). 'Motivational interviewing for modifying diabetes risk: a randomised controlled trial'. *British Journal of General Practice* 58 (553): 535–40.
- Greenhalgh T, Heath I (2010). *Measuring Quality in the Therapeutic Relationship*. London: The King's Fund. Available at: www.kingsfund.org.uk/current_projects/gp_inquiry/dimensions_of_care/the_therapeutic.html (accessed on 18 August 2010).
- Greening L, Greaves I, Greaves N, Jolley D (2009). 'Positive thinking on dementia in primary care: Gnosall Memory Clinic'. *Community Practitioner* 82 (5): 20–23.

Griffiths C, Foster G, Ramsey J, Eldridge S, Taylor S (2007). 'How effective are expert patient (lay led) education programmes for chronic disease?'. *British Medical Journal* 334: 1254–56.

Gupta S, Hawker GA, Laporte A, Croxford R, Coyte PC (2005). 'The economic burden of disabling hip and knee osteoarthritis (OA) from the perspective of individuals living with this condition'. *Rheumatology* 44 (12): 1531–37.

Ham C (2006). *Reducing Unplanned Admissions to Hospital: What does the literature tell us?*. Birmingham: HSMC, University of Birmingham.

Ham C, York N, Sutch S, Shaw R (2003). 'Hospital bed utilisation in the NHS, Kaiser Permanente, and the US Medicare programme: analysis of routine data'. *British Medical Journal* 327: 1257.

Health Dialog (2006). *Combined Predictive Model: Final report*. London: The King's Fund. Available at: www.kingsfund.org.uk/research/projects/predicting_and_reducing_readmission_to_hospital/#tab4 (accessed on 10 September 2009).

Healthcare Commission (2007). *Managing Diabetes. Improving services for people with diabetes*. Service review. London: Healthcare Commission.

Hippisley-Cox J, Fielding K, Pringle M (1998). 'Depression as a risk factor for ischaemic heart disease in men: population based case control study'. *British Medical Journal* 316: 1714–19.

Hippisley-Cox J, O'Hanlon S, Coupland C (2004). 'Association of deprivation, ethnicity, and sex with quality indicators for diabetes: population based survey of 53,000 patients in primary care'. *BMJ* 329 (7477): 1267–69.

Hutt R, Rosen R, McCauley J (2004). *Case Managing Long Term Conditions*. London: King's Fund.

Hutt R, Rosen R (2005). 'A chronic case of mismanagement?'. *Journal of Health Services Research Policy* 10 (4): 194–95.

Illiffe S, Wilcock J, Haworth D (2006). 'Obstacles to shared care for patients with dementia: a qualitative study'. *Family Practice* 23: 353–62.

Jagger C, Matthews R, Spiers N, Brayne C, Comas-Herrera A, Robinson T, Lindesay J, Croft P (2006). *Compression or Expansion of Disability? Forecasting future disability levels under changing patterns of diseases*. Wanless Social Care Review research report. Leicester: Leicester Nuffield Research Unit.

Jenkins R, McCulloch A, Friedli L, Parker C (2002). *Developing a National Mental Health Policy*. Maudesley monograph 43. Hove: The Psychology Press.

Jessep SA, Walsh NE, Ratcliffe J, Hurley MV (2009). 'Long-term clinical benefits and costs of an integrated rehabilitation programme compared with outpatient physiotherapy for chronic knee pain'. *Physiotherapy* 95 (2): 94–102.

Johnston O, Kumar S, Kendall K, Peveler R, Gabbay J, Kendrick T (2007). 'Qualitative study of depression management in primary care: GP and patient goals, and the value of listening'. *Br J Gen Pract* 57 (544): 872–79.

Jordan KM, Sawyer S, Coakley P, Smith HE, Cooper C, Arden NK (2004). 'The use of conventional and complementary treatments for knee osteoarthritis in the community'. *Rheumatology* 43 (3): 381–84.

Kadam UT, Jordan K, Croft PR (2004). 'Clinical comorbidity in patients with osteoarthritis: a case-control study of general practice consultants in England and Wales'. *Ann Rheum Dis* 63 (4): 408–14.

Kates N, Mach M (2007). 'Chronic disease management for depression in primary care: a summary of the current literature and implications for practice'. *Can J Psychiatry* 52 (2): 77–85.

Katon WJ, Seelig M (2008). Population-Based Care of Depression: Team Care Approaches to Improving Outcomes. *JOEM*, 50 (4), 459–167.

Kilbourne AM, Schulberg HC, Post EP, Rollman BL, Belnap BH, Pincus HA (2004). 'Translating evidence-based depression management services to community-based primary care practices'. *Milbank Q* 82 (4): 631–59.

Kisely S, Campbell LA (2007). 'Taking consultation-liaison psychiatry into primary care'. *Int J Psychiatry Med* 37 (4): 383–91.

Kisely S, Smith M, Lawrence D, Cox M, Campbell LA, Maaten S (2007). 'Inequitable access for mentally ill patients to some medically necessary procedures'. *CMAJ* 176 (6): 779–84.

Knapp M, Comas-Herrera A, Somani A, Banerjee S (2007). *Dementia: International comparisons*. Summary report. London: National Audit Office. Available at: www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx (accessed on 26 August 2009).

Koch T, Illiffe S (2009). 'Implementing the National Dementia Strategy: case studies from primary care'. *Journal of Dementia Care* 17 (6): 26–29.

Kumar K, Daley E, Carruthers DM, Situnayake D, Gordon C, Grindulis K, Buckley CD, Khattak F, Raza K (2007). 'Delay in the presentation to primary care physicians is the main reason why patients with rheumatoid arthritis are seen late by rheumatologists'. *Rheumatology* 46 (9): 1438–40.

Kupfer DJ (1991). 'Long-term treatment of depression'. *Journal of Clinical Psychiatry* 52 (5): 28–34.

Layard R (2006). 'The case for psychological treatment centres'. *BMJ*, 332: 1030–32.

Lewis R, Dixon J (2004). 'Rethinking management of chronic diseases'. *British Medical Journal* 328: 220–22.

Lin P, Campbell DG, Chaney EF, Liu CF, Heagerty P, Felker BL, Hedrick SC (2005). 'The influence of patient preference on depression treatment in primary care'. *Ann Behav Med* 30 (2): 164–73.

Linsell L, Dawson J, Zondervan K, Randall T, Rose P, Carr A, Fitzpatrick R (2005). 'Prospective study of elderly people comparing treatments following first primary care consultation for a symptomatic hip or knee'. *Family Practice* 22: 118–25.

Lloyd KR, Jenkins R, Mann A (1996). 'Long-term outcome of patients with neurotic illness in general practice'. *BMJ* 313 (7048): 26–28.

Luqmani R, Hennell S, Estrach C, Basher D, Birrell F, Bosworth A, Burke F, Callaghan C, Candal-Couto J, Fokke C, Goodson N, Homer D, Jackman J, Jefferson P, Oliver S, Reed M, Sanz L, Stableford Z, Taylor P, Tood N, Warburton L, Washbrook C, Wilkinson M (2009). *British Society for Rheumatology and British Health Professionals in Rheumatology Guidelines for the Management of Rheumatoid Arthritis (After the First Two Years)*.

London: British Society for Rheumatology. Available at: www.rheumatology.org.uk/guidelines/clinicalguidelines/raposttwo (accessed on 23 June 2009).

MacLean CH, Saag KG, Solomon DH, Morton SC, Sampsel S, Klippel JH (2004). 'Measuring quality in arthritis care: methods for developing the Arthritis Foundation's quality indicator set'. *Arthritis and Rheumatism* 15 (2): 193–202.

Mauro M, Taylor V, Wharton S and Sharma AM (2008). 'Barriers to obesity treatment'. *European Journal of Internal Medicine* 19 (3): 173–80.

McGovern MP, Williams DJ, Hannaford PC, Taylor MW, Lefevre KE, Boroujerdi MA, Simpson CR (2008). 'Introduction of a new incentive and target-based contract for family physicians in the UK: good for older patients with diabetes but less good for women?'. *Diabetic Medicine* 25 (9): 1083–89.

McHugh GA, Luker KA, Campbell M, Kay PR, Silman AJ (2007). 'A longitudinal study exploring pain control, treatment and service provision for individuals with end-stage lower limb osteoarthritis'. *Rheumatology* 46 (4): 631–37.

McManus S, Meltzer H, Brugha T, Bebbington P, Jenkins R (2009). *Adult Psychiatric Morbidity in England, 2007. Results of a household survey*. Leeds: NHS Information Centre.

Sederer LI, Silver L, McVeigh KH, Levy J (2006). 'Integrating care for medical and mental illnesses'. *Prev Chronic Dis* 3 (2): A33.

Melzer D, Fryers T, Jenkins R (2004). *Social Inequalities and the Distribution of the Common Mental Disorders*. Maudsley monographs. Hove: Psychology Press.

Memel DS, Somerset M (2003). 'General practitioner and specialist care: the perceptions of people with rheumatoid arthritis'. *Primary Health Care Research and Development* 4 (1): 29–37.

Mezuk B, Eaton WW, Albrecht S, Golden SH (2008). 'Depression and type 2 diabetes over the lifespan: a meta-analysis'. *Diabetes Care* 31 (12): 2383–90.

Mulnier HE, Seaman HE, Raleigh VS, Soedamah-Muthu SS, Colhoun HM, Lawrenson RA, de Vries CS (2006). 'Risk of stroke in people with type 2 diabetes in the UK: a study using the General Practice Research Database'. *Diabetologia* 49 (12): 2859–65.

Narasimhan M, Raynor JD, Jones AB (2008). 'Depression in the medically ill: diagnostic and therapeutic implications'. *Curr Psychiatry Rep* 10 (3): 272–79.

National Audit Office (2009). *Services for People with Rheumatoid Arthritis*. London: NAO. Available at: www.nao.org.uk/publications/0809/rheumatoid_arthritis.aspx (accessed on 20 July 2009).

National Audit Office (2008). *Pay Modernisation: New contracts for general practice services in England*. London: NAO. Available at: www.nao.org.uk/publications/0708/new_contracts_for_general_prac.aspx (accessed on 6 August 2009).

National Audit Office (2007a). *Dementia Focus Group Findings*. Final report. London: PricewaterhouseCoopers LLP/NAO. Available at: www.nao.org.uk/publications/0607/dementia_services_and_support.aspx (accessed on 26 August 2009).

National Audit Office (2007b). *Improving Services and Support for People With Dementia*. London: NAO. Available at: www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx (accessed on 26 August 2009).

Narasimhan M, Raynor JD, Jones AB (2008). 'Depression in the medically ill: diagnostic and therapeutic implications'. *Curr Psychiatry Rep* 10 (3): 272–79.

National Institute for Health and Clinical Excellence (2010). *Type 1 Diabetes: Diagnosis and management of type 1 diabetes in children, young people and adults*. Clinical guideline 15. (Originally dated July 2004, updated April 2010). London: NICE. Available at: <http://guidance.nice.org.uk/CG15/NICEGuidance/pdf/English> (accessed on 30 July 2010).

National Institute for Health and Clinical Excellence (2009a). *Depression: The treatment and management of depression in adults (update)*. NICE guideline. Draft for consultation. London: NICE.

National Institute for Health and Clinical Excellence (2009b). *Depression: The treatment and management of depression in adults with chronic physical health problems*. NICE guideline. Draft for consultation. London: NICE.

National Institute for Health and Clinical Excellence (2009c). *Rheumatoid Arthritis. Costing report. Implementing NICE guidance*. NICE website. Available at: www.nice.org.uk/nicemedia/pdf/CG79CostingReport.pdf (accessed on 22 June 2009).

National Institute for Health and Clinical Excellence (2009d). *The Management of Rheumatoid Arthritis in Adults*. Clinical guideline 79. NICE website. Available at: www.nice.org.uk/nicemedia/pdf/CG79NICEGuideline.pdf (accessed on 22 June 2009).

National Institute for Health and Clinical Excellence (2008a). *Osteoarthritis. Costing report. Implementing NICE guidance*. Available at: www.nice.org.uk/nicemedia/pdf/OsteoarthritisCostingReport.pdf (accessed on 22 June 2009).

National Institute for Health and Clinical Excellence (2008b). *The Care and Management of Osteoarthritis in Adults*. Clinical guideline 59. NICE website. Available at: www.nice.org.uk/nicemedia/pdf/CG59NICEguideline.pdf (accessed on 22 June 2009).

National Institute for Health and Clinical Excellence (2008c). *Type 2 Diabetes. National clinical guideline for management in primary and secondary care (update)*. NICE website. Available at: www.nice.org.uk/nicemedia/pdf/CG66FullGuideline0509.pdf (accessed on 10 August 2009).

National Institute for Health and Clinical Excellence (2007). *Donepezil, Galantamine, Rivastigmine (review) and Memantine for the Treatment of Alzheimer's Disease (amended)*. NICE technology appraisal guidance 111. NICE website. Available at: www.nice.org.uk/nicemedia/pdf/TA111fullversionamendedSept07.pdf (accessed on 26 August 2009).

National Institute for Health and Clinical Excellence (2004). *Type 1 Diabetes: Diagnosis and management of type 1 diabetes in children, young people and adults*. Available at: www.nice.org.uk/nicemedia/pdf/CG015NICEGuidelineUpdate.pdf (accessed on 10 August 2009).

National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006a). *Dementia. Supporting people with dementia and their carers in health and social care*. NICE clinical guideline 42. NICE website.

Available at: www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf (accessed on 26 August 2009).

National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006b). *Audit Criteria – Dementia*. NICE clinical guideline no 42. London: NICE/SCIE.

Nell VPK, Machold KP, Eberl G, Stamm TA, Uffmann M, Smolen JS (2004). 'Benefit of very early referral and very early therapy with disease-modifying anti-rheumatic drugs in patients with early rheumatoid arthritis'. *Rheumatology* 43 (7): 906–14.

NHS Choices (2010). 'Dementia: Introduction'. NHS Choice website. Available at: www.nhs.uk/conditions/Dementia/Pages/Introduction.aspx (accessed on 26 August 2009).

NHS Diabetes (2009). *NICE and Diabetes: A summary of the relevant guidelines*. London: NHS. Available at: www.diabetes.nhs.uk/tools_and_resources/reports_and_guidance/ (accessed on 15 April 2010).

NHS Information Centre (2010). *National Diabetes Audit. Executive summary*. NHS diabetes specialist library website. Leeds: NHS Information Centre. Available at: www.library.nhs.uk/Diabetes/ViewResource.aspx?resID=379534 (accessed on 3 August 2010).

NHS Information Centre (2008). *National Diabetes Audit. Executive summary. Key findings about the quality of care for people with diabetes in England and Wales*. Report for the audit period 2007/8. Leeds: NHS Information Centre. Available at: www.ic.nhs.uk/webfiles/Services/NCASP/audits%20and%20reports/7121_National%20Diabetes%20Audit_final.pdf (accessed on 10 August 2009).

Noel PH, Frueh BC, Larme AC, Pugh JA (2005). 'Collaborative care needs and preferences of primary care patients with multimorbidity'. *Health Expect* 8 (1): 54–63.

Noel PH, Parchman ML, Williams JW Jr, Cornell JE, Shuko L, Zeber JE, Kazis LE, Lee AF, Pugh JA (2007). 'The challenges of multimorbidity from the patient perspective'. *J Gen Intern Med* 22 (3): 419–24.

Nutting PA, Goodwin MA, Flocke SA, Zyzanski SJ, Stange KC (2003). 'Continuity of primary care: to whom does it matter and when?' *Ann Fam Med* 1 (3): 149–55.

Nuyen J, Spreeuwenberg PM, van DL, den Bos GA, Groenewegen PP, Schellevis FG (2008). 'The influence of specific chronic somatic conditions on the care for co-morbid depression in general practice'. *Psychol Med* 38 (2): 265–77.

Offredy M, Bunn F, Morgan J (2009). 'Case management in long term conditions: an inconsistent journey'. *British Journal of Community Nursing* 14 (6): 252–7.

Ogle KS, Swanson GM, Woods N, Azzouz F (2000). 'Cancer and comorbidity: redefining chronic diseases'. *Cancer* 88 (3): 653–63.

Olfson M, Mechanic D, Boyer C, Hansell S, Walkup J, Weiden P (1999). 'Assessing Clinical Predictions of Early Rehospitalization in Schizophrenia'. *Journal of Nervous and Mental Diseases* 187 (12): 721–729.

- Osborn D, Levy G, Nazareth I (2007). 'Relative risk of cardiovascular and cancer mortality in people with severe mental illness from the United Kingdom's General Practice Research Database'. *Archives of General Psychiatry* 64: 242–49.
- Oxman TE, Dietrich AJ, Schulberg HC (2005). 'Evidence-based models of integrated management of depression in primary care'. *Psychiatr Clin North Am* 28 (4): 1061–77.
- Parchman ML, Noel PH, Lee S (2005). 'Primary care attributes, health care system hassles, and chronic illness'. *Med Care* 43 (11): 1123–29.
- Porcheret M, Jordan K, Jinks C, Croft P (2007). 'Primary care treatment of knee pain – a survey in older adults'. *Rheumatology* 46 (11): 1694–1700.
- Rait G, Walters K, Bottomley C, Petersen I, Iliffe S, Nazareth I (2010). 'Survival of people with clinical diagnosis of dementia in primary care: cohort study'. *BMJ* 341: c3584.
- Rheumatology Futures Group (2009). '18 week Commissioning Pathway Inflammatory Arthritis (Joint Pain)'. NHS 18 weeks website. Available at: www.18weeks.nhs.uk/Content.aspx?path=/achieve-and-sustain/Specialty-focussed-areas/rheumatology/inflammatory-arthritis/ (accessed on 22 July 2009).
- Richards DA, Lovell K, Gilbody S, Gask L, Torgerson D, Barkham M, Bland M, Bower P, Lankshear AJ, Simpson A, Fletcher J, Escott D, Hennessy S, Richardson R (2008). 'Collaborative care for depression in UK primary care: a randomized controlled trial'. *Psychol Med* 38 (2): 279–87.
- Rogers A, Kennedy A, Bower P (2008). 'The United Kingdom Expert Patients Programme: results and implications from a national evaluation'. *Med J Aust* 189 (10): S21–S24.
- Roland M, Dusheiko M, Gravelle H, Parker S (2005). 'Follow up of people aged 65 and over with a history of emergency admissions: analysis of routine admission data'. *British Medical Journal* 330: 289–92.
- Royal College of General Practitioners (2009). *Care of People with Mental Health Problems*. RCGP curriculum statement 13. London: RCGP.
- Roy-Byrne PP, Stein MB, Russo JE, Craske MG, Katon WJ, Sullivan G, Sherbourne CD (2005). 'Medical illness and response to treatment in primary care panic disorder'. *General Hospital Psychiatry* 27 (4): 237–43.
- Sampson MJ, Dozio N, Ferguson B, Dhatariya K (2007). 'Total and excess bed occupancy by age, specialty and insulin use for nearly one million diabetes patients discharged from all English Acute Hospitals'. *Diabetes Research and Clinical Practice* 77 (1): 92–98.
- Scott J (2006). 'Depression should be managed like a chronic disease'. *BMJ* 332: 985–86.
- Sederer L, Silver L, McVeigh K, Levy J (2006). 'Integrating care for medical and mental illnesses'. *Preventing Chronic Disease* 3 (2): 1–3.
- Segal L, Day SE, Chapman AB, Osborne RH (2004). 'Can we reduce burden of disease from osteoarthritis?'. *Medical Journal of Australia* 180 (5), S11–17.
- Sheppard J, Kumar K, Buckley CD, Shaw KL, Raza K (2008). "'I just thought it was normal aches and pains": a qualitative study of decision-making

- processes in patients with early rheumatoid arthritis'. *Rheumatology* 47 (10): 1577–82.
- Simmons RK, Unwin N, Griffin SJ (2010). 'International Diabetes Federation: an update of the evidence concerning the prevention of type 2 diabetes'. *Diabetes Research and Clinical Practice* 87 (2): 143–49.
- Simon GE, Goldberg DP, Von Korff M, Ustun TB (2002). 'Understanding cross-national differences in depression prevalence'. *Psychological Medicine* 32 (4), 585–94.
- Soljak MA, Majeed A, Eliahoo J, Dornhorst A (2007). 'Ethnic inequalities in the treatment and outcome of diabetes in three Primary Care Trusts'. *International Journal for Equity in Health* 6:8. Available at: www.equityhealthj.com/content/6/1/8/abstract (accessed on 22 June 2009).
- Starfield B, Lemke KW, Bernhardt T, Foldes SS, Forrest CB, Weiner JP (2003). 'Comorbidity: implications for the importance of primary care in "case" management'. *Ann Fam Med* 1 (1): 8–14.
- Steel N, Maisey S, Clark A, Fleetcroft R, Howe A (2007). 'Quality of clinical primary care and targeted incentive payments. An observational study'. *British Journal of General Practice* 57 (539): 449–54.
- Steel N, Bachmann M, Maisey S, Shekelle P, Breeze E, Marmot M and Melzer D (2008). 'Self reported receipt of care consistent with 32 quality indicators: national population survey of adults aged 50 or more in England'. *BMJ* 337 (132): 438–52.
- Steffens DC, Rama Krishnan KR (1998). 'Psychotherapeutic agents in older adults. Metabolism, bioavailability and drug interactions'. *Clinics in Geriatric Medicine* 14: 17–31.
- Steward K and Land M (2009). *Perceptions of Patients and Professionals on Rheumatoid Arthritis Care*. London: The King's Fund.
- Struijs JN, Baan CA, Schellevis FG, Westert GP, van den Bos GA (2006). 'Comorbidity in patients with diabetes mellitus: impact on medical health care utilization'. *BMC Health Serv Res* 6: 84.
- Tahrani AA, McCarthy M, Godson J, Taylor S, Slater H (2008). 'Impact of practice size on delivery of diabetes care before and after the Quality and Outcomes Framework implementation'. *British Journal of General Practice* 58 (553): 576–79.
- Turner S, Illiffe S, Downs M, Wilcock J, Bryans M, Levin E, Keady J, O'Carroll R (2004). 'General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia'. *Age and Ageing* 33: 461–67.
- Tylee A, Walters P (2007). 'We need a chronic disease management model for depression in primary care'. *Br J Gen Pract* 57 (538): 348–50.
- van Weel-Baumgarten EM (2005). 'Is depression a chronic illness? A response from the perspective of general practice'. *Chronic Illn* 1 (2): 113–15.
- Victor CR, Ross F, Axford J (2004). 'Capturing lay perspectives in a randomized control trial of a health promotion intervention for people with osteoarthritis of the knee'. *Journal of Evaluation in Clinical Practice* 10 (1): 63–70.

Wagh N, Scotland G, McNamee P, Gillet P, Brennan A, Goyder E, Williams R, John A (2007). 'Screening for type 2 diabetes: literature review and economic modelling'. *Health Technology Assessment* 11 (17): iii-iv, ix-xi, 1–125. Available at: www.hta.ac.uk/fullmono/mon1117.pdf (accessed on 15 April 2010).

Wagner EH, Simon GE (2001). 'Managing depression in primary care'. *BMJ* 322 (7289): 746–47.

Wennberg D, Siegel M, Darin B, Filipova N, Russell R, Kenney L, Steinort K, Park TR, Cakmakci G, Dixon J, Curry N, Billings J (2006). *Combined Predictive Model*. Final report. London: The King's Fund. Available at: www.kingsfund.org.uk/current_projects/predicting_and_reducing_readmission_to_hospital/#resources (accessed on 10 July 2010).

World Health Organization (2008). *The Global Burden of Disease. 2004 update*. Geneva: WHO.

Yorkshire and Humber Public Health Observatory (2008). *Diabetes in England*. York: YPHO. Available at: www.library.nhs.uk/DIABETES/ViewResource.aspx?resID=300742 (accessed on 11 August 2009).

Young A, Dixey J, Kulinskaya E, Cox N, Davies P, Devlin J, Emery P, Gough A, James D, Prouse P, Williams P, Winfield J (2002). 'Which patients stop working because of rheumatoid arthritis? Results of five years' follow up in 732 patients from the Early RA Study (ERAS)'. *Annals of Rheumatic Disorder* 61 (4): 335–40.

Young D, Furler J, Vale M, Walker C, Segal C, Dunning P, Best J, Blackberry I, Audehm R, Sulaiman N, Dunbar J and Chondros P (2007). 'Patient engagement and coaching for health: the PEACH study – a cluster randomised controlled trial using the telephone to coach people with type 2 diabetes to engage with their GPs to improve diabetes care: a study protocol'. *Biomed Central Family Practice*. 8 (20): 1–9. Available at: www.ncbi.nlm.nih.gov/pmc/articles/PMC1854904/ (accessed on 20 April 2010).

Appendix 1 Literature review study terms and example of results

All searches used a common 'base' (column A) plus topic-specific search terms (column B). Articles had to contain one term from column A, and one from B. The search was limited to the last 10 years only and title/abstract only (apart from depression which was title only).

A	B				
	Arthritis	Dementia	Diabetes	Depression	Co-morbidity
GP	Arthritis	Alzheimer's disease	Blood glucose	Depression	Co-morbidity
General practice	Inflammatory	Dementia (and	Diabetes (and	Mental health	Dual diagnosis
General	arthritis	variants)	variants)	Mental illness	Multi-morbidity
practitioner	Joint pain	Memory clinic	Insulin	Mental disorder	Multiple needs
Primary care	Musculoskeletal	Memory loss		Psychiatric (and	Multiple care needs
	Osteoarthritis			variants)	Multiple chronic
	Rheumatoid				Multiple long-term
	arthritis				
	Rheumatism				

Appendix 2 Sample protocol for interviews with expert informants

Expert informant: interview guide

[Sample]

Preamble:

Discuss the nature of the Inquiry, why they have been chosen to participate, what the interview is about, and how long it will take. Ask permission to record interview, stressing all data will be stored securely and only used for the purposes of the Inquiry. Ask the interview for any questions or points of clarification

Introduction – role, experience, expertise

To provide us with an understanding of your experience and expertise, I would like to start by asking you to say a bit about yourself – your role (current job), your experience and involvement with regard to the issue of quality of care for people with [insert long-term condition here] in general practice.

Condition-specific questions

I want to start by asking about high-quality care for people with [insert condition] generally, and then move on to focus specifically on the role of general practice within that.

1. In an ideal world, what would **high-quality care for people with [depression]** look like in general terms (in other words, regardless of location of care)?
 - In an ideal world what would *best quality care look like or contain for a patient with [condition]*? [prompt about care pathways]
 - Is there much *evidence or guidance* to tell us what best quality of patient care should look like?
 - How useful are *models of care* for managing these patients? [prompt – for example, collaborative care, care management]. What components of these are most important?
2. What do you think the **role of general practice** should be, in the delivery of such high-quality care for people with [insert condition]?
 - What things lie within the *core role of general practice*, and what enhanced roles could there be – for example, for *GPs with a special interest*? Enhanced services by a practice-based team?

[Prompt: Discuss GP role in advice giving, diagnosis, referral to services treatment, ongoing monitoring, supported self care].
 - What role does self-care play?

[Prompt: Self care is advice and support to enable people to live healthy and at home, ongoing relationship between patient and general practice].

- What role should *other staff* within the practice play – for example, staff nurses, practice managers, receptionists?
3. You've described what management of [insert condition] should look like in general practice – **how close are we to that, in reality?**
- What is your impression generally of the quality of care provided by general practices?
 - What is the extent of *variations in quality*? [Ask about variations in terms of area, deprivation, gender, ethnicity, practice size/level etc.]
 - What accounts for the variations? What *impedes best quality care* in general practice for people who suffer with [insert condition]?
 - What are the key areas in which *general practice as a whole could improve the quality of care* it provides to patients with [insert condition]?
4. What **quality improvement tools or approaches** could be used to improve the quality of care for [depression] in general practice?
- If you were attempting to measure the quality of care provided to people with [insert condition] by general practice, what would be the *key measures of quality* you might use?
 - Are there any *current measures* that you are aware of that are currently being used to measure quality? What are these? Are these measures suitable?
 - Is using measures and metrics a useful approach to quality improvement? What other approaches could be used?

People with multiple long-term conditions

I'd like to talk now about people with more than one long-term condition, and how their needs should be managed.

5. Would high-quality **care for patients with multiple LTCs be different than for people with a single condition?**
- Are there any particular *models of care* that are appropriate for people with multiple LTCs (eg 'guided care')?
6. How about the **role of general practice** – would that **look different** for people with multiple LTCs compared to those only with [insert condition]?
- How *close are we to that vision of best practice in reality*? Any areas for improvement? Extent of variations in quality, and reasons for this.
 - What areas would you focus on to make the biggest difference in care quality?
 - Are current *measures of quality of care* any different for people with *multiple LTCs*? How suitable are they for people with multiple LTCs?

Population management

I want to ask about taking proactive approaches to the management of people with LTCs. Proactive population management – identifying patients who might be at increased risk of developing long-term conditions, or identifying those with an existing diagnosis whose risk of deterioration is increasing.

7. [ONLY ASK IF THE INTERVIEWEE IS A PRACTISING GP]. Do you undertake any **proactive population management of your registered patients**?
 - Do you run any *screening/preventative/pre-emptive* programme to identify those most at risk of deterioration or unplanned admission to hospital for example?
 - How do you make sure you target this proactive care at the *right patients*? Is this an accurate method?
 - What sort of *interventions* do you offer to patients identified as being at risk? Do you offer different sorts of care to different patients, depending on the level of risk?
8. What are the **pros and cons** of GPs taking proactive approaches to managing all their registered patients for LTCs (not just those already identified with a LTC)?
 - How important do you think this proactive or pre-emptive work is in management of LTCs? Is it a key part of the role of the GP? If not, who should be offering it?

Implications for general practice

Finally, I'd like to ask about the implications of what we've been talking about for the general model of general practice used in this country.

9. Do you think the model of general practice needs to **adapt in a broader** or more **fundamental** sense in order to meet the needs of patients with [insert condition]?
 - If so, how should it adapt?
10. Do you know of any examples of best practice that would be worth investigating as a case example? [single LTC or multiple LTC]
 - Prompt for details and contacts.

Thank you for participating in this interview about the quality of long-term conditions management in general practice.

Would you be interested in attending an expert seminar in [give date if possible] to discuss the quality of long-term conditions management in general practice?

Appendix 3 Number and types of expert informants interviewed

Type of informant	B				
	Arthritis	Dementia	Diabetes	Depression	Total
GP or GP with a special interest	3	3	2	5	13
LTC nurse or other primary care professional	1	1	1	1	4
PCT commissioner	1	-	1	0	2
Policy-maker	1	1	1	1	4
Academic	3	2	2	2	9
Representative of patient group or society	2	4	2	1	9
Total	11	11	9	10	41

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Delivering better services for people with long-term conditions

Building the house of care



Key messages

- The management of care for people with long-term conditions should be proactive, holistic, preventive and patient-centred. This report describes a co-ordinated service delivery model – the ‘house of care’ – that incorporates learning from a number of sites in England that have been working to achieve these goals.
- The house of care model differs from others in two important ways: it encompasses all people with long-term conditions, not just those with a single disease or in high-risk groups; and it assumes an active role for patients, with collaborative personalised care planning at its heart. Implementing the model requires health care professionals to abandon traditional ways of thinking and behaving, where they see themselves as the primary decision-makers, and instead shifting to a partnership model in which patients play an active part in determining their own care and support needs.
- In personalised care planning, clinicians and patients work together using a collaborative process of shared decision-making to agree goals, identify support needs, develop and implement action plans, and monitor progress. This is a continuous process, not a one-off event.
- An important feature of the approach is the link between care planning for individuals and commissioning for local populations; it aims to make best use of local authority services (including social care and public health) and community resources, alongside more traditional health services.
- The house of care metaphor is used to illustrate the whole-system approach, emphasising the interdependency of each part and the various components that need to be in place to hold it together. Care planning is at the centre of the house; the left wall represents the engaged and informed patient, the right wall represents the health care professional committed to partnership working, the roof represents organisational systems and processes, and the base represents the local commissioning plan.

- Each of these components has been introduced in one or more primary care sites around England. While few sites have yet succeeded in putting all the components together in one place, all agree on the need to do so to ensure a well-functioning, sustainable system.
- Building the house involves a wide variety of organisations, professional groups and individuals working together in a co-ordinated manner, pooling budgets, sharing data and learning how to get better at delivering holistic, co-ordinated, person-centred care. The report makes a number of **recommendations** on how NHS England, clinical commissioning groups (CCGs), Health Education England, the Department of Health and provider groups can work together to support the transformational change that is needed to improve care for people with long-term conditions.

Background

The need to improve the treatment and management of long-term conditions is the most important challenge facing the NHS. Improving care for people with long-term conditions must involve a shift away from a reactive, disease-focused, fragmented model of care towards one that is more proactive, holistic and preventive, in which people with long-term conditions are encouraged to play a central role in managing their own care.

It is now widely recognised that the care and support needed to live with a long-term condition requires a radical re-design of services, allowing patients to drive the care planning process. Yet despite extensive lobbying from patient groups and numerous policy documents calling for such change, progress on the ground has been slow, with little improvement over the past 10 years. Many of the elements needed to support change have been developed, drawing on international best practice, but they remain isolated and fragmented. Top-down exhortation and targets have failed to influence change and clinical behaviour at the grassroots.

The missing component – a practical, robust, reproducible and transferable delivery system developed by practitioners and service users in England – is now available. Based on the house of care developed and tested by the Year of Care programme (Diabetes UK *et al* 2011), this model differs from other approaches in that it takes, as its starting point, the active involvement of patients in developing their own care plans through a shared decision-making process with clinicians. It is rooted in primary care but addresses the whole system of care, including community resources. It also provides commissioning groups with a roadmap for developing a responsive, whole-person delivery system.

More than 3,000 practitioners and 60 trainers working in 26 communities around England are now involved in **the house of care**. Meanwhile, other programmes such as **QIPP Right Care**, **Co-creating Health**, **MAGIC** (Making Good Decisions in Collaboration), **Personal Health Budgets** and **People Powered Health** have developed complementary strategies designed to ensure that every person with a long-term condition has an opportunity to participate in a collaborative care planning process with effective self-management support.

Earlier in 2013, representatives of these groups and others came together at a workshop organised by The King's Fund to discuss their experiences, share learning and identify ways in which this practical knowledge could be applied across the country (*see Appendix*). In preparation for the workshop, we interviewed several participants to gain a deeper understanding of how they were tackling the shift to a more collaborative model.

This report outlines the key points of their collective learning. We describe the building blocks that make up the house of care and the strategies developed by local teams to

ensure that each of the components is feasible in English primary care settings. We also outline some of the difficulties that must be overcome to produce a fully working model. The house of care has now been adopted as a central metaphor in NHS England's plans for improving care for people with long-term conditions (McShane and Mitchell 2013). It is therefore crucial that commissioners and providers understand the implications of this whole-system change and are clear about what needs to be in place to ensure the successful implementation of the house of care model.

We hope this report will provide a good starting point for CCGs and others wanting to promote more productive partnerships between patients and clinicians. We believe this approach can deliver more effective self-management, better co-ordinated care and improved health outcomes for people living with long-term conditions.

Policy context

Chronic diseases are now the most common cause of death and disability in England. More than 15 million people have a long-term condition such as hypertension, depression, asthma, diabetes, coronary heart disease, chronic kidney disease, or other health problem or disability for which there is no cure. These people tend to be heavy users of health care resources, accounting for at least 50 per cent of all general practitioner (GP) appointments, 64 per cent of outpatient appointments and 70 per cent of all inpatient bed days (Department of Health 2012a). Special analysis of 'Social Care at the End of Life' project data indicates that an estimated 18 per cent of people with long-term conditions are in receipt of state-funded social care (T Georghiou, personal communication 2013), and a small proportion of those with the most disabling or complex conditions (less than 1 per cent of the total) receive NHS Continuing Care support and are currently eligible for personal health budgets (Department of Health 2013).

The prevalence of long-term conditions rises with age, affecting about 50 per cent of people aged 50, and 80 per cent of those aged 65. Many older people have more than one chronic condition, but in absolute terms there are more people with long-term conditions under the age of 65 than in older age groups.

Recent analysis of patient data from Scotland found that 42 per cent of the population had at least one long-term condition and 23 per cent had two or more (Barnett *et al* 2012). Most people aged over 65 had multi-morbidities, but the onset of multi-morbidity occurred 10–15 years earlier among those living in deprived areas; people in these areas were also more likely to experience mental health problems alongside physical illness or disability than people in more affluent areas.

The total number of people with a long-term condition in England is projected to be relatively stable over the next 10 years, but the number of people with multiple conditions is projected to rise to 2.9 million in 2018, from 1.9 million in 2008 (Department of Health 2012a).

A growing body of evidence underscores the importance of effective self-management of long-term conditions (Epping-Jordan *et al* 2004). People who are more 'activated' (that is, who recognise that they have an important role in self-managing their condition and have the skills and confidence to do so) experience better health outcomes (Greene and Hibbard 2012). With effective support and education, evidence shows that these skills can be developed and strengthened, even among those who are initially less confident, less motivated or have low levels of health literacy (Hibbard and Greene 2013).

The **Chronic Care Model**, which has influenced health policy around the world, stresses the need to transform health care for people with long-term conditions from a system that

is largely reactive – responding mainly when a person is sick – to one that is much more proactive, and focuses on supporting patients to self-manage (Wagner 1998). This assumes an active role for patients, who are encouraged to become both more knowledgeable about factors affecting their condition and more actively involved in decisions about their care. It is also based on a conviction that local communities have multiple resources that can be mobilised to help people live healthier and more fulfilled lives.

People with long-term conditions are managing their health on a daily basis, but they may need additional help to develop their confidence in fulfilling their role as a self-manager. This may include support to enhance their ability to manage their tests or medicines, to make changes to their lifestyle or to cope with the emotional and social consequences of living with a long-term condition (Corbin and Strauss 1988). Primary care teams that are willing and able to signpost their patients to appropriate support, including community resources, can do much to improve the quality of people's lives (Diabetes UK 2011).

The call for a more person-centred, better co-ordinated approach to managing care for people with long-term conditions has been embraced by numerous advisory bodies, advocacy groups, governments and international agencies. For instance, National Voices – a coalition of more than 140 UK health and social care charities – developed a first-person narrative to explain what the gold standard of care looks like. This requires making the patient perspective (or that of the service user) the organising principle of integrated care, and can be summarised as follows: 'I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me' (National Voices 2013).

A report by the Richmond Group of Charities and The King's Fund (2012) outlined the service components needed to achieve this:

- patients engaged in decisions about their care
- supported self-management
- co-ordinated care
- prevention, early diagnosis and intervention
- emotional, psychological and practical support.

These demands have not fallen on deaf ears in Whitehall. The government's [Mandate](#) for NHS England requires it to 'ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment' (Department of Health 2012b). This includes the aspiration that everyone with a long-term condition, including those with mental health problems, should be offered a personalised care plan that reflects their preferences and agreed decisions.

Building the house of care

While there is now a consensus on the need to transform the model of care for people with long-term conditions, up until now there has been less clarity about the specific changes required. Many integrated care pilot schemes have been launched, most of which share the same goal – a new service delivery system that leads to better outcomes for specific groups of patients (Nuffield Trust and The King's Fund 2013; Roland *et al* 2012; Newbould *et al* 2012; Burt *et al* 2012; Bardsley *et al* 2013; Nuffield Trust and Imperial College London 2013). But few of these have succeeded in transforming the relationship between patients and clinicians. The management and care of long-term conditions still tends to be seen as the clinician's responsibility rather than a collaborative endeavour with active patient involvement and effective self-management support.

The house of care metaphor was devised to help those working in primary care adapt the chronic care model to their own situation. It explicitly places the patient at the heart of the delivery system. Its key elements are as follows.

- People with long-term conditions are central to the process. They are supported by health and social care professionals to express their own needs and decide on their own priorities through a process of information-sharing, shared decision-making and action planning.
- Self-management support and the development of collaborative relationships between patients and professionals are at the heart of service delivery. This shifts the focus onto the roles and responsibilities of patients as well as professionals, and the systems that are needed to support them to fulfil these roles. The ultimate aim is that people should have the knowledge, skills and confidence to manage their condition effectively in the context of their everyday life.
- Tackling health inequalities is a central aim of the house of care. The number of long-term conditions and their burden falls disproportionately on people with poor health literacy and those in lower socio-economic groups. Tools, skills training and ongoing support must be available to identify those who find it harder to engage with health issues and may need extra support to do so.
- The house of care delivery system aims to ensure that each individual is involved in a unified, holistic care planning process with a single care plan. A common set of relevant skills and processes reduces the burden of training.
- Quality assurance of the philosophy, core approach and skills required is essential to ensure that implementation builds on relevant evidence and experiential knowledge, which is consistently applied.
- Care planning is the gateway to personalisation and/or personal health budgets.

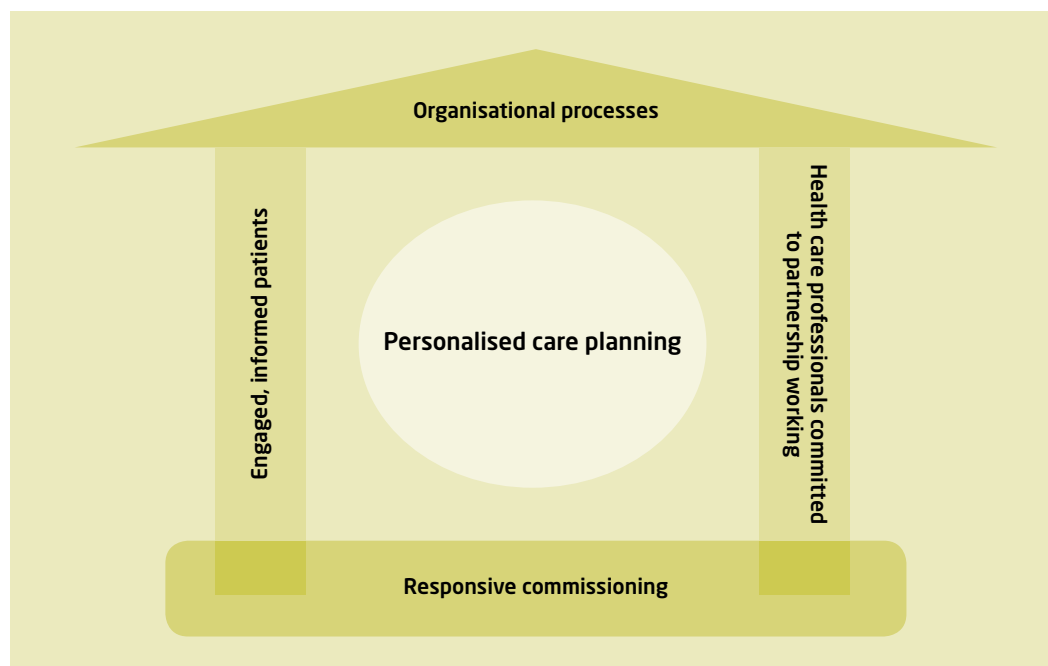
In 2007, Diabetes UK and the Department of Health launched an ambitious pilot project to explore ways of introducing and embedding this new type of delivery system into routine care for people with long-term conditions, using diabetes as an exemplar (Diabetes UK *et al* 2011). The starting point was to get primary care staff to model new types of collaborative conversations, encouraging patients to articulate their needs, decide on priorities, agree goals, and jointly develop a plan for achieving these. The ultimate aim was to develop a robust, systematic and reproducible approach, transferable to any setting and for people with any long-term condition or more than one condition, while also ensuring that each person received a uniquely personalised service.

Evaluation of the pilot phase of the Year of Care programme revealed improvements in patients' experience of care and in self-care behaviour (Diabetes UK *et al* 2011). Professionals gained new knowledge and skills, leading to greater job satisfaction. Practice organisation, teamwork and productivity improved, and progress could be seen across relevant clinical indicators after two or three care planning cycles.

It quickly became apparent that embedding this new approach more widely would require fundamental changes to the organisation, delivery and commissioning of primary care. The metaphor of a house was used to describe the issues that each primary care team needed to address to make care planning possible (Figure 1).

The house of care reinforces the whole-system approach needed and acts as both a metaphor and an implementation checklist. As a metaphor, it emphasises the interdependence of each of the components, enabling the new style of clinical consultation. If one 'wall' is weak, the structure is not fit for purpose. As a checklist, it provides a reproducible mechanism to identify the essential processes and systems that

Figure 1 The house of care



promote awareness, engagement and clarity across clinical teams, stimulating reflection on the building blocks available locally and areas that may need prioritisation for improvement.

Personalised care planning is at the centre of the house. This is a collaborative process designed to bring together the perspectives and expertise of both the individual and the professional(s) involved in providing care, offering tailored personal support to develop the confidence and competence needed for effective self-management.

The two side walls of the house – engaged, informed patients and health care professionals committed to partnership working – are equally important. Patients may need extra encouragement to participate in a more active way than they are used to, so consideration needs to be given to preparing them for this new role. Staff need to understand this new way of working, value the contribution that each person can bring to their care and develop the skills to support self-management. Partnership working also extends to colleagues, as care for people with long-term conditions will increasingly be provided by multidisciplinary teams, both within general practice but also linking with wider community, social care and specialist staff.

The roof of the house represents the robust organisational systems that are essential to ensure efficient processes, including reliable systems for identifying and contacting patients with long-term conditions, flexible appointment systems that support linked contacts and allow for longer consultations when necessary, and record systems that can be used to document and share care plans, and for monitoring outcomes.

All this requires the firm foundation of a responsive local commissioning system. Care planning itself – and the systems and training needed to support it – must be explicitly commissioned; the menu of community groups and services must be developed, and a robust measurement system must be in place.

The house of care model provides a structure for transferring learning from site to site in a reproducible way, with each of its elements developed locally, based on local needs. The process of transfer is equally important, ensuring that cultural as well as

administrative components are reliably addressed. The critical success factors developed during repeated cycles of delivery and feedback provide the core of a quality-assured training and support programme.

We now describe each of the five components of the house in more detail, with examples of how they are being delivered in primary care settings, drawing on discussions with workshop participants and interviewees. We also explore some of the challenges likely to be faced when implementing this new delivery system, and our strategies for overcoming any barriers.

The centre of the house – personalised care planning

From the perspective of a person living with a long-term condition, the contacts they have with health and social care services make up only a very small proportion of their daily life. The larger part is spent managing their condition(s), drawing on their own resources and those available in the wider community – many of which can have a significant positive effect on outcomes (Horne *et al* 2013).

The few hours per year these individuals currently spend with health care professionals are often inadequately used to inform and support them or connect them with others who could provide support, representing both poor use of resource and a missed opportunity. Personalised care planning directly addresses this problem.

Collaborative personalised care planning aims to ensure that individuals' values and concerns shape the way in which they are supported to live with and self-manage their long-term condition(s). Instead of focusing on a standard set of disease management processes, this approach encourages people with long-term conditions to work with clinicians to determine their specific needs and express informed preferences for treatment, lifestyle change and self-management support. Then, using a decision coaching process, they agree goals and action plans for implementing them, as well as a timetable for reviewing progress. It is a continuous or cyclical process or pathway involving several steps (Figure 2).

Where care planning takes place, how frequently, with whom, and how each step is designed will vary according to local resources and individuals' needs. The important point is that care planning, implementation and review is a continuous process over a period of months or years, not a single one-off event.

It is acknowledged that having better conversations between clinicians and patients is not something that can be achieved without additional effort. Clinicians already have a structure for consultations 'hardwired' into their daily practice. Old habits die hard, so it is important to be clear about what exactly needs to change to implement this new way of working.

The biggest change for clinicians involves recognising that the information about the lived experience and personal assets that the patient brings to the care planning process is as important as the clinical information in the medical record; processes also need to be in place to help the clinician identify and include the patient's contribution. Once this is recognised, the subsequent stages happen more naturally – moving through a systematic process of sharing information, discussing options, setting goals and developing an action plan (Figure 3). But adopting this new approach requires clinicians to fundamentally reconsider their professional role – from working in a reactive system that treats people with long-term conditions when they become ill to working in a proactive system that supports those people to stay well. This means that clinicians need to work with patients in a different way, demanding new skills and knowledge and new ways of thinking, and involve themselves in new ways of working to ensure that the 'person's story' is effectively included.

Figure 2 Care planning – a cyclical process

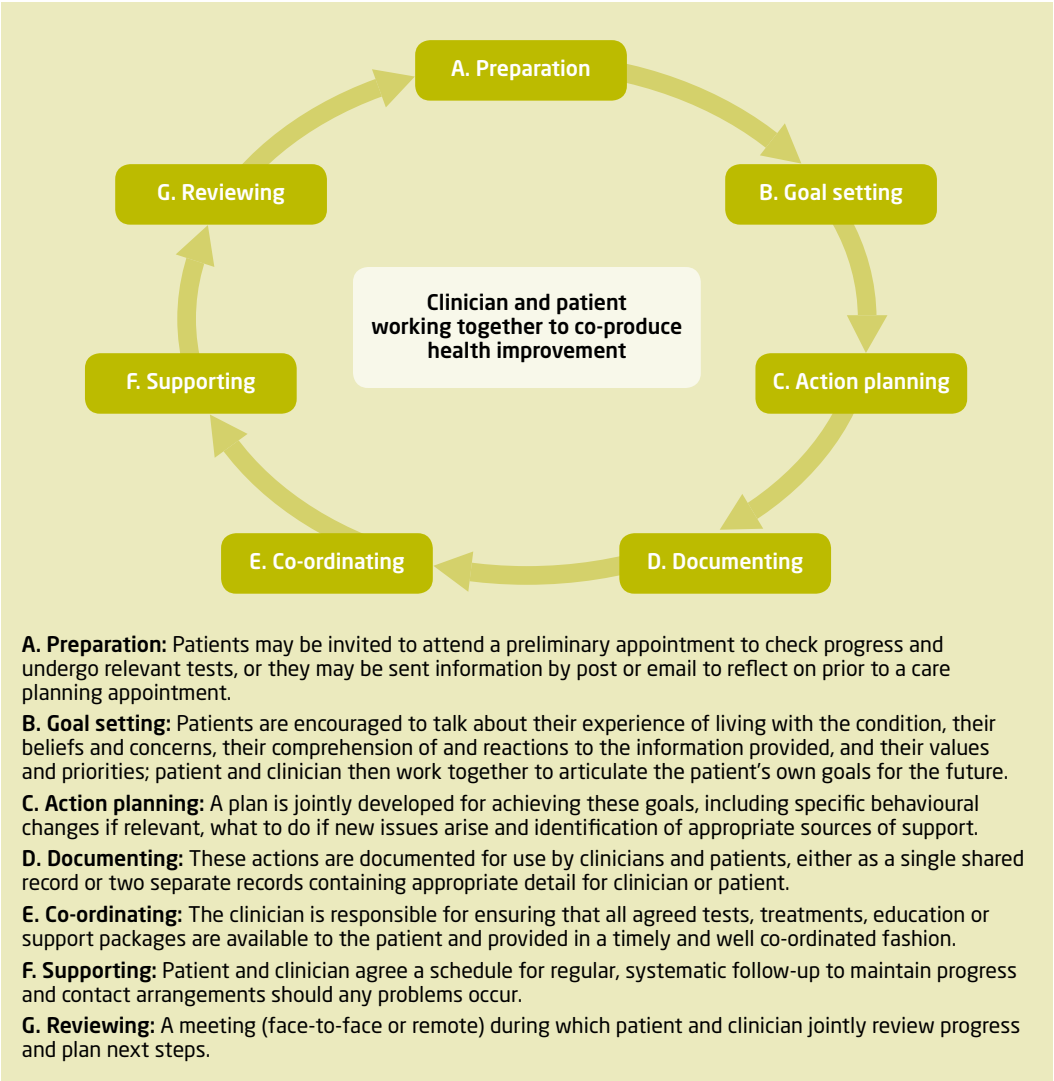


Figure 3 The new consultation – a systematic approach



Practitioners with experience of using a collaborative approach to care planning emphasised the importance of giving each individual the right amount of time for a consultation, and the benefits of a common approach for those with single or multiple long-term conditions. In some places, care planning is now being used to signpost people to community resources and support and as a first step in designing their personal health budgets.

Clinicians often complain that time pressures get in the way of providing the type of personalised care they would like to be able to deliver. Our informants described contrasting ways of dealing with this problem. For some, it involved careful prioritisation so that the person's most important issues were focused on first, with planned follow-up consultations to deal with secondary issues. For others, it meant offering longer consultations for those who needed them, in the belief that this approach makes the whole pathway more efficient.

The right consultation for each patient

Practices involved in the Year of Care programme offered longer appointments for care planning consultations for people with a long-term condition. Most often 20 minutes was sufficient, especially when tests and examinations were performed in advance. A risk stratification approach enabled some to offer 30–40 minute appointments when greater needs were identified.

Nurses took responsibility for consultations with patients whose health condition was relatively straightforward, while GPs dealt with those who had multi-morbidities or more complex problems.

Those who had embraced this way of working wanted more specific help to support those of their colleagues who were struggling to adapt their consultation styles. They also wanted advice on how to help those patients who were finding adopting effective self-management skills and making lifestyle changes especially difficult.

Where care planning had been introduced relatively easily for a single condition such as diabetes, participants reflected on the challenge of doing this at scale if every individual with a long-term condition were to be included, particularly those with mental health issues and learning disabilities.

Participants and interviewees remarked on the extra administrative complexity of organising care planning for people with multiple long-term conditions. While it proved challenging to bring together all the clinical issues for each individual with multiple conditions into one holistic care plan, the potential benefits of doing so were immense.

Many of those we talked to commented on the difficulty of knowing just what was going on in consultations, and whether the way clinicians and patients worked together had really changed. There was a strong demand for better ways of measuring patients' experiences and patient-reported outcomes, so that progress can be carefully monitored.

While in each case an example of success existed somewhere, there can be little doubt that the introduction of care planning on the scale envisaged will require significant changes across primary care practice as a whole.

Integrated health and care planning

Community health teams are using care planning with people with complex problems, linking them to support services in the community. Training in how to do this has been successfully adapted for integrated health and social care teams. This approach has been used for people with cardiovascular conditions, those with chronic obstructive pulmonary disease, and among older people with multiple conditions.

Care planning offers both a personalised solution for each individual and a means of identifying the variety of support needs in a local area. It achieves person-centred co-ordinated care by:

- linking support for self-management with high-quality clinical care
- co-ordinating health and social care across boundaries and teams
- signposting to community resources, where appropriate.

More profoundly, care planning becomes the pivot that transforms a reactive model of care, treating patients when they are sick, into a proactive one that aims to help people keep active and well for as long as possible.

The left wall of the house – engaged, informed patients

Most people want to take more control of their health and would like to be informed and involved in discussions about how to manage any conditions they may have. Patients may not expect to play a leading role in managing their health and reaching shared decisions with health care professionals, so taking active steps to prepare them for this new way of working can be helpful.

While the overall care planning process is cyclical, the need to ensure individual engagement in each care planning ‘conversation’ led to the key idea of a two-stage process. This involves: (1) actively seeking out the person’s views and providing them with personalised information in the form of prompts, decision aids and reflective sheets; and (2) building in time to reflect and discuss with family and friends before the consultation itself.

The sharing of information in the ‘two-stage’ consultation was highly valued. This means the conversation starts with both parties being better informed. For some, this involved collating and sending out test results and explanations, as in the original diabetes pilot; for others, signposting to tailored information prescriptions or patient decision aids that focus on a planned area of discussion helped to prepare patients for an active role in the care planning process. Patients are encouraged to come with a list of issues or concerns they would like to discuss with the health professional. This can then be used to set the agenda for the care planning consultation.

Agenda setting

Bolton Primary Care Trust worked with the Design Council to develop a set of 40 agenda cards that patients could use to describe how they feel about having diabetes. These helped to bring out the hidden dimensions of the challenges of self-care and allowed clinicians to spend less time on diagnosis and more time on co-developing and agreeing a care plan.

Primary care teams have developed a number of pre-consultation tools, including questionnaires, reflection sheets and patient decision aids for consultations where specific decisions have to be made.

Decision support

The **Pennine MSK Partnership** is a service set up in conjunction with NHS Oldham to provide an integrated care pathway for people with musculoskeletal problems. The team is led by two GPs with an interest in rheumatology, and a nurse consultant.

Referral to the team triggers access to specially designed decision aids that tell patients about different options for managing their condition, and the pros and cons of each option. This prepares them for an active role and encourages shared decision-making.

A number of evidence-based patient decision aids are now freely available on websites such as **NHS Choices** and **Patient.co.uk**.

Collaborative care planning is not confined to primary care; secondary care clinics can make good use of it too.

Care planning in secondary care

Care planning using a two-stage process is now established in routine diabetes outpatient clinics and specialist insulin pump clinics for people with diabetes in **Nottingham City Hospital**. Specialist staff and health care assistants as well as patients are enthusiastic about the improved teamwork that has resulted from working and training together in this new way.

Some patients may need additional support to enable them to become effective self-managers. This might include referral to structured education programmes, such as **DESMOND** for type 2 diabetes, or six-week generic self-management courses such as those run under the auspices of the **Expert Patients Programme**. Such courses can help people to develop practical skills and strategies for dealing with the emotional and psychological impact of living with a long-term condition.

In addition to the educational impact of courses, many patients value the social support gained from meeting other people who are living with a long-term condition. Referral to community or self-help groups can serve the same function. Self-help groups have the added advantage of being user-controlled and not time-limited.

Outside a care planning format, other approaches to encourage effective involvement have been developed, including record access schemes such as **Patients Know Best**, or social marketing campaigns such as **Ask 3 Questions** (see box on p 12), both of which are designed to legitimise the patient's role as an active partner or co-producer in managing their health.

Social marketing

Practices in Newcastle and Cardiff involved in the Health Foundation's **MAGIC** (Making Good Decisions in Collaboration) project and those involved in the **Right Care Shared Decision Making** programme distributed leaflets encouraging patients to ask three questions about their treatment:

- What are my options?
- What are the pros and cons of each option for me?
- How do I get support to make a decision that's right for me?

These were accompanied by a **video** in which patients talked about how they used these questions to understand their care and get more involved. The video could be accessed on Newcastle Hospital website and was played in practice waiting areas.

Various strategies have been used to encourage patient participation, including making information available about care planning and how people can be involved (either by letter or using display screens in waiting rooms), and engaging the wider community, local champions and faith groups.

People told us that the greatest barrier to getting these approaches more widely adopted was negative attitudes on the part of health professionals. Health and social care professionals may also be unaware of local community and self-help resources and their potential benefits. However, experience at a number of sites demonstrated that these attitudes could be overcome, given the right support and training. Many primary care sites and CCGs have produced directories of community resources to aid information exchange and referral.

The right wall of the house – professionals committed to partnership working

Health care professionals who do things *with* people rather than *to* them can achieve so much more, but this is not sufficiently emphasised in most training programmes. On first hearing about the collaborative partnership approach required for personalised care planning, many clinicians say 'we do that already'. However, those who attend development workshops or training courses quickly learn that there are things they can improve on. Often they find that their usual consulting style is not as collaborative as they thought it was.

Recognising the central role of patients in the day-to-day self-management of their conditions, and the professional's role in supporting each patient to develop the knowledge, skills and confidence to be an expert self-manager, is the first step to professional engagement.

Clinicians need to learn to practise a consulting style that is curious, supportive and non-judgemental, which uses problem-solving and coaching techniques, and contains the following elements (Coulter and Collins 2011):

- developing empathy and trust
- negotiating agenda setting and prioritising
- sharing information
- challenging and re-attributing unhelpful beliefs
- communicating and managing risk

- supporting deliberation
- summarising and feeding back
- developing action plans collaboratively
- documenting agreed actions
- providing practical and emotional follow-up support.

Judicious use of role play, feedback, self-assessment and lay involvement in skills workshops can help to create those ‘light bulb’ moments that are the important first step towards developing new attitudes and a commitment to learning new skills. Training together as a team or with specialist colleagues can provide an environment that is conducive to change and improves partnership working with colleagues too. The good news is that once professionals are engaged in shared decision-making with patients and actively supporting them in self-management, they often describe it as a better way of working. Positive feedback from patients in the form of questionnaire responses reinforces the benefits of adopting the approach.

Developing care planning skills

Newcastle West Clinical Commissioning Group has provided care planning training for GPs across all their 18 practices as part of a **People Powered Health** project. The Year of Care programme team adapted the training to cover mental health issues because these tend to get forgotten when staff focus on physical health.

Role play and interactive DVD exercises were used to create the ‘light bulb’ moments when participants realise that, contrary to what they think about involving patients in their care, they are not ‘doing it already’.

Effective leadership from professional bodies will be key to embedding the type of culture change that is needed if personalised care planning is to become the norm. Until recently, these bodies were disappointingly slow to adopt a leadership role in this area; but a few colleges and professional societies have begun to lead the way.

Clinical leadership

The **Royal College of General Practitioners** has announced that care planning is a quality marker of best practice in the 21st century. It is embarking on an ambitious programme to embed care planning across general practice, starting with the creation of communities of practice (each involving 6 to 12 general practices) working on specific clinical conditions. Ultimately, the aim is to develop a model that works for patients with multi-morbidities and ensures that the competencies to deliver care planning are incorporated and assessed in professional training.

Meanwhile, the **Royal College of Physicians** has appointed a fellow in shared decision-making with a remit to introduce the concept to each of the college’s specialist societies and their members, and to share good practice.

Numerous courses are now available for clinicians as well as patients, covering a wide variety of competencies relevant to the management of long-term conditions, but these are of variable quality. Courses that combine a challenge to traditional attitudes and behaviours with providing a safe environment in which to practise new skills and identify the type of procedures and system changes that are needed have had a strong impact on professional behaviour.

Quality assurance

The **Quality Institute for Self Management Education & Training (QISMET)** is an independent body that sets standards and certificates providers of training in self-management, patient education and self-care. QISMET certification covers all aspects of managing and running high-quality education programmes. It is currently developing standards for self-management support services.

The roof of the house – organisational processes

Many of the primary care teams involved in the Year of Care programme found that they needed to adapt their clinic infrastructure and working practices. Some made significant changes to the way the workforce was deployed, with more support for administrative and task-based roles to free up clinical staff for the longer consultations that were needed.

The ability to record, analyse and use information in new ways is another key aspect in making the system work efficiently, ensuring that patients receive the right level of support. For primary care teams, this means knowing their practice population and ensuring that they have the capacity to identify people who should be invited to attend for care planning consultations. This may involve reviewing and upgrading IT systems in a number of respects: to check contact details; for risk stratification and identification; to merge results into personalised letters; to facilitate the administration of linked appointments; to send out prompts, test results, information prescriptions or decision aids; to record patients' goals; and to ensure that summaries and plans are available in written as well as electronic form, for use by patients as well as clinicians.

Participants reported numerous successes in solving practical issues in specific areas such as coding, putting decision aids on the web, developing recall systems and 'navigators', and using measurement routinely. This provides considerable experience on which to build a sophisticated suite of support tools.

IT systems

Practices in Kirklees, West Yorkshire, tested IT templates that enable individuals' goals and action plans to be incorporated into the clinical record alongside traditional test results. This demonstrated the potential to stimulate practice improvement as well as feed into local commissioning plans for community support.

People at the top of the long-term conditions pyramid (Figure 4) – those with complex needs who have the highest risk of needing more intensive care and support – tend to be high users of both health and social care. In many places, they have to undergo multiple assessments by different health and social care professionals who do not communicate with each other. Integrated record systems, data-sharing and pooled budgets are the basic building blocks of a more joined-up system that should provide less fragmented care.

Data-sharing

Cumbria Partnership NHS Foundation Trust has made significant investments over three years to build robust IT systems that allow data-sharing. As a result, 90 per cent of their general practices and community services now use the same system. Clinical information can be shared across the local health economy, and it is also possible to link with social care data.

However, despite these successes, IT issues remained the biggest challenge for participants, after professional engagement.

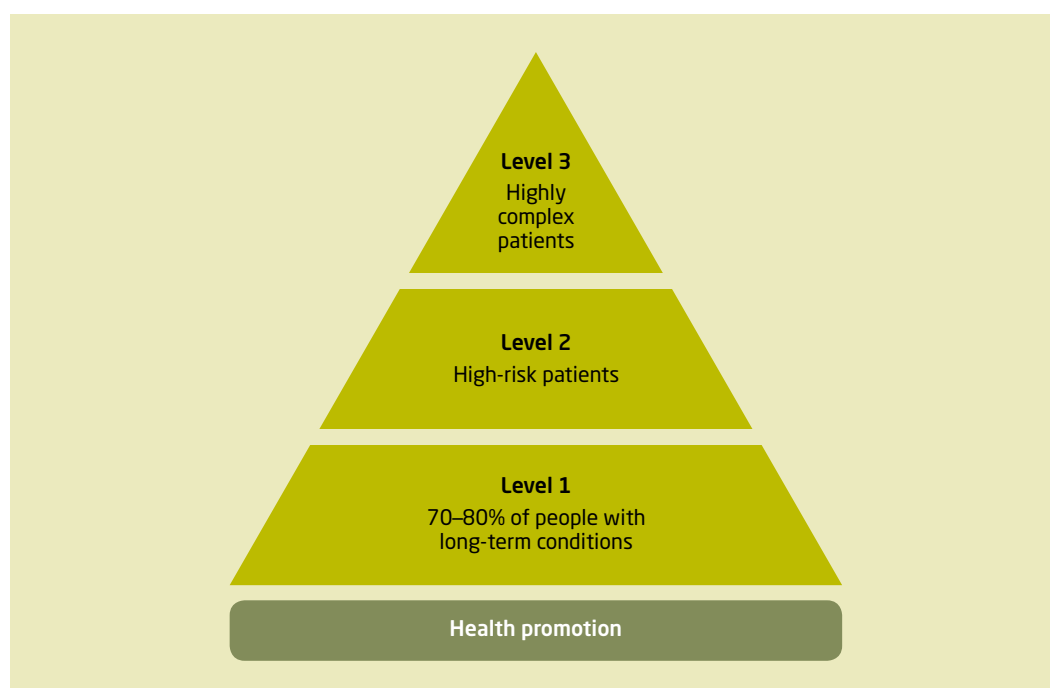
Risk stratification and case-finding systems use a combination of hospital and primary care data to predict the likelihood of hospital admission, but some of our informants felt that linking in social care data would produce a more complete picture of what is going on across their locality. This might enable commissioners to integrate care and target resources more accurately. The gold standard would be fully interoperable systems that allow data to be shared between different local services.

A basic issue for many of those we spoke to was how to ensure that the administrative and recording functions to support care planning were incorporated as standard in electronic health record systems; no one had achieved this completely.

The foundations of the house – responsive commissioning

Many commissioning bodies see considerable potential for improving efficiency by reducing demand for unscheduled hospital admissions and accident and emergency (A&E) attendances. Primary care trusts (PCTs) and now CCGs are making extensive use of predictive modelling tools to identify needs and target people at high risk of hospital admission in an attempt to control costs – focusing on the top of the long-term conditions pyramid (Figure 4).

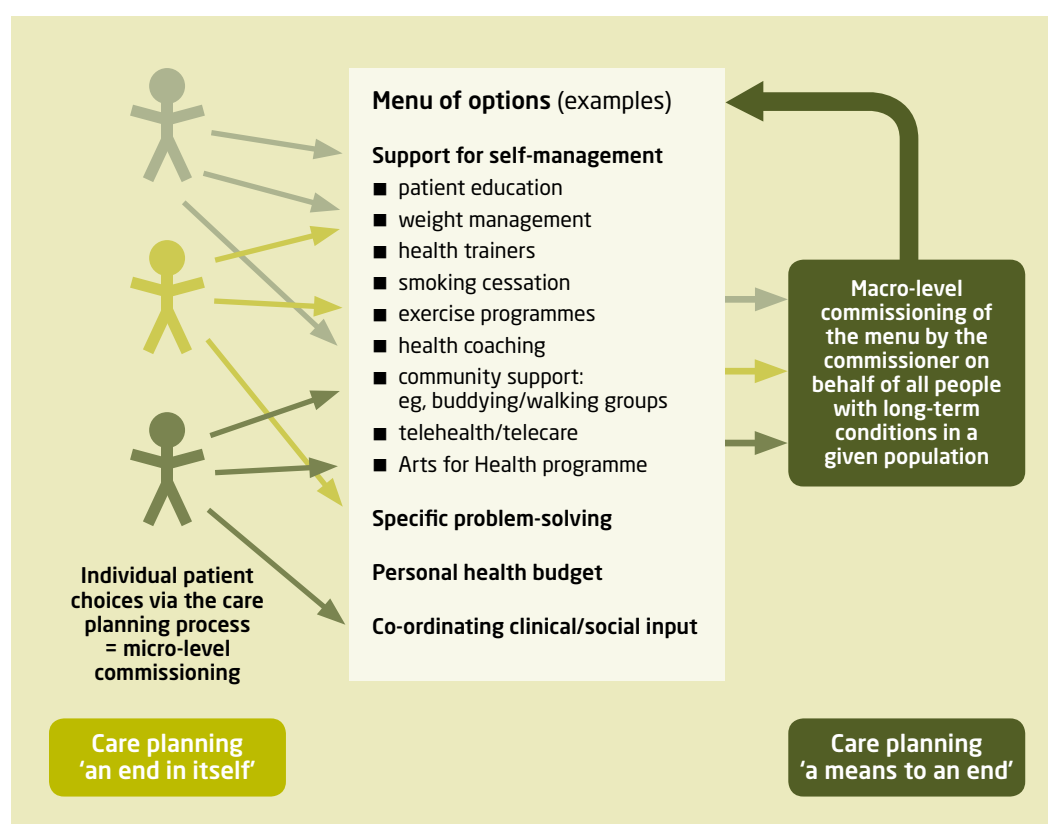
Figure 4 Matching support to needs



A high-risk approach can be a good place to start; frail older people in particular and those approaching the end of their lives have an important need for special support in their own right. But since these groups comprise a relatively small proportion of the local population, targeting a much wider group with preventive care and self-management support is probably a better way to achieve benefits that are measurable across a local health economy (Roland and Abel 2012). A comprehensive strategy for *all* people with long-term conditions based on a common approach is what concerns us here.

The house of care model integrates personalised care planning for individuals with responsive commissioning for populations. Individual needs and choices identified during the care planning process (micro-level commissioning) are aggregated to provide a local commissioning plan (Figure 5). In this way, commissioners can match services to their population as well as to each person.

Figure 5 From care planning to population commissioning



The support needs identified during the care planning process may not be confined to those normally supplied by traditional health services; community and self-help groups can often provide the type of support to people with long-term conditions that statutory services tend to ignore (Diabetes UK 2011). Examples include cookery classes to help those struggling to eat a healthy diet, gardening projects to encourage physical exercise, volunteer befriending schemes to combat social isolation and loneliness, advice centres, and peer-led self-help groups.

This type of 'social prescribing' depends on staff having good knowledge of what services are available in their local community. Mapping local community groups and services into electronic health directories to facilitate signposting and referral is an important component of the house of care.

In some places, community health trainers are being commissioned to offer direct information and support where needed (*see box*).

Community health trainers

HealthWORKS Newcastle has recruited and trained local people to work as community health trainers, providing a variety of support services for people with long-term conditions. For example, health trainers help patients attending the lipid clinic at Newcastle's Royal Victoria Infirmary to improve their lifestyle by linking advice and practical support around smoking, stress, diet, alcohol, physical activity and obesity.

Other community health champions, based in local primary schools, are working with parents to tackle priority issues such as child health and obesity.

Encouraging self-help

Self Help Nottingham has more than 30 years' experience of supporting self-help groups for people with various long-term conditions in Nottingham and across the rest of England.

In addition to helping more than 200 groups to get established, including finding funding, organising publicity and campaigning, they provide training courses for staff in the principles and practice of shared experience and self-care support.

They are also working with CCGs, local authorities and voluntary organisations, helping them to create supportive environments for self-help groups and to systematise self-care support provided by self-help groups and the third sector.

Aggregating the support needs identified by individuals into a commissioning plan for a locality requires robust electronic records and systems for data-sharing. It also requires the identification of a portfolio or menu of local services for people to choose from and a willingness on the part of commissioners to fund non-traditional services. This might include a wide variety of options, from telehealth to peer support, depending on local requirements (Diabetes UK 2011).

Recent evidence suggests that encouraging greater emphasis on anticipatory care, better support for self-management and better use of community assets could create greater value at lower cost than is possible with the current fragmented network of services. Nesta, a UK charity that promotes innovation, has estimated that this could produce savings of around £4.4 billion per year if fully implemented (Morioka *et al* 2013). The evaluation of the **Personal Health Budgets** pilots found that a personalised approach had significant positive effects on patients' quality of life and emotional wellbeing (Forder *et al* 2012).

However, these optimistic conclusions were not reflected in the findings of several other recent studies of self-management support (Bardsley *et al* 2013; Kennedy *et al* 2013; Bucknall *et al* 2012; Fan *et al* 2012). This may be because specific components – for example, patient involvement in goal setting and action planning – were not given sufficient priority in the evaluated programmes, or it may be due to the difficulties inherent in implementing the type of whole-system change that we believe is necessary.

At a local level, the importance of human factors cannot be overstressed. Disappointing results from some telehealth schemes underline the folly of assuming that the answer lies simply in the provision of more technical tools and kit, or relying on single interventions without taking account of the local context and the need for system change (Steventon *et al* 2012). Care planning should be monitored to check that it is being practised as intended, and commissioners will need to ensure that the menu of care and support services is relevant and up to date. The importance of a systematic process to sustain this and to link the whole model together, in the form of steering groups and practice facilitators, cannot be overemphasised.

The NHS is awash with small-scale improvement initiatives, but care planning and self-management support needs to be implemented across multiple organisations covering much wider geographical areas if it is to make a real impact. Success depends on building effective local partnerships between NHS, social care, public health and community organisations and, where necessary, provision of appropriate support from NHS England and other national bodies.

CCGs will need to be ambitious if they are to change traditional ways of working and realise the benefits in terms of better outcomes and greater value for money. Our informants assured us that many organisations are keen to raise their game in this way, and there are several examples of ambitious strategic plans that are in the process of being implemented.

Investing for change

Cumbria Clinical Commissioning Group has committed £1 million per year over the next three to five years to fund training and skills development for the care of people with long-term conditions, including improvement collaboratives, train the trainers programmes, pathway development, capacity-building, and management support for change and innovation.

Developing integrated systems

Kent County Council aims to provide anticipatory care for people at the highest risk by integrating health and social care. The local authority is working closely with NHS organisations to apply integrated health and social care assessment and personalised care planning, using mechanisms such as pooled budgets, integrated practitioners, integrated personal health and social care budgets, patient-held records and linked data systems.

Monitoring progress

Use of appropriate metrics for monitoring progress is essential in any quality improvement programme, and the house of care model is no exception. The methods may include obtaining systematic feedback from patients using validated questionnaires to check that they are being involved in developing their care plans. Once there is agreement on goals and these are linked to reliable measures, then incentives can be put in place to encourage improvements. Many of the groups we spoke to had struggled to find locally appropriate measures that could be easily applied, analysed and fed back.

Metrics to incentivise improvements

The **Personal Health Budgets** pilot sites agreed to measure the effects of budget-holding on bio-medical markers and hospital admissions. No changes were observed in the clinical indicators, but admission rates reduced significantly and patients' quality of life and emotional wellbeing improved (Forder *et al* 2012).

Measurement was also an important feature of **AQuA's Shared Decision Making project**, where several patient questionnaires were used to monitor progress, none of which was entirely satisfactory. Those involved in the **MAGIC** programmes in Newcastle and Cardiff developed special codes that were incorporated into EMIS software packages to monitor shared decision-making consultations.

In some cases, Quality and Outcomes Framework (QOF) scores may be sufficient. For example, Tower Hamlets practices were delighted to find that they moved from the bottom of the league table for diabetes care to very near the top after introducing care planning.

The purpose of personalised care planning is to ensure that people with long-term conditions are given personalised support to develop the knowledge, skills and confidence they need to effectively manage their health. Several instruments have been developed to measure these attributes, including the Patient Activation Measure (PAM) (Hibbard *et al* 2005), the Patient Enablement Instrument (PEI) (Howie *et al* 1998), the Patient Partnership in Care (PPIC) instrument (Powell *et al* 2009), the Self-Management Ability Scale (SMAS-30) (Cramm *et al* 2012), the Partners in Health (PIH) scale (Battersby *et al* 2003), the Patient Assessment of Chronic Illness Care (PACIC) (Schmittiel *et al* 2008) and the Consultation and Relational Empathy (CARE) measure (Mercer *et al* 2004), to name a few.

Commissioners may want to use indicators such as these to monitor the impact of this new way of working on population health. CCGs might also want to encourage their providers to focus on improving these metrics for people at low levels of activation or with low health literacy, thus driving the system to reduce health inequalities. Providers might make use of these or other similar measures to ensure that they are undertaking personalised care planning and self-management support to the highest possible standard. For example, measures of patient experience and decision quality can be used to check the extent to which the patient was informed about their options and involved in the care planning process.

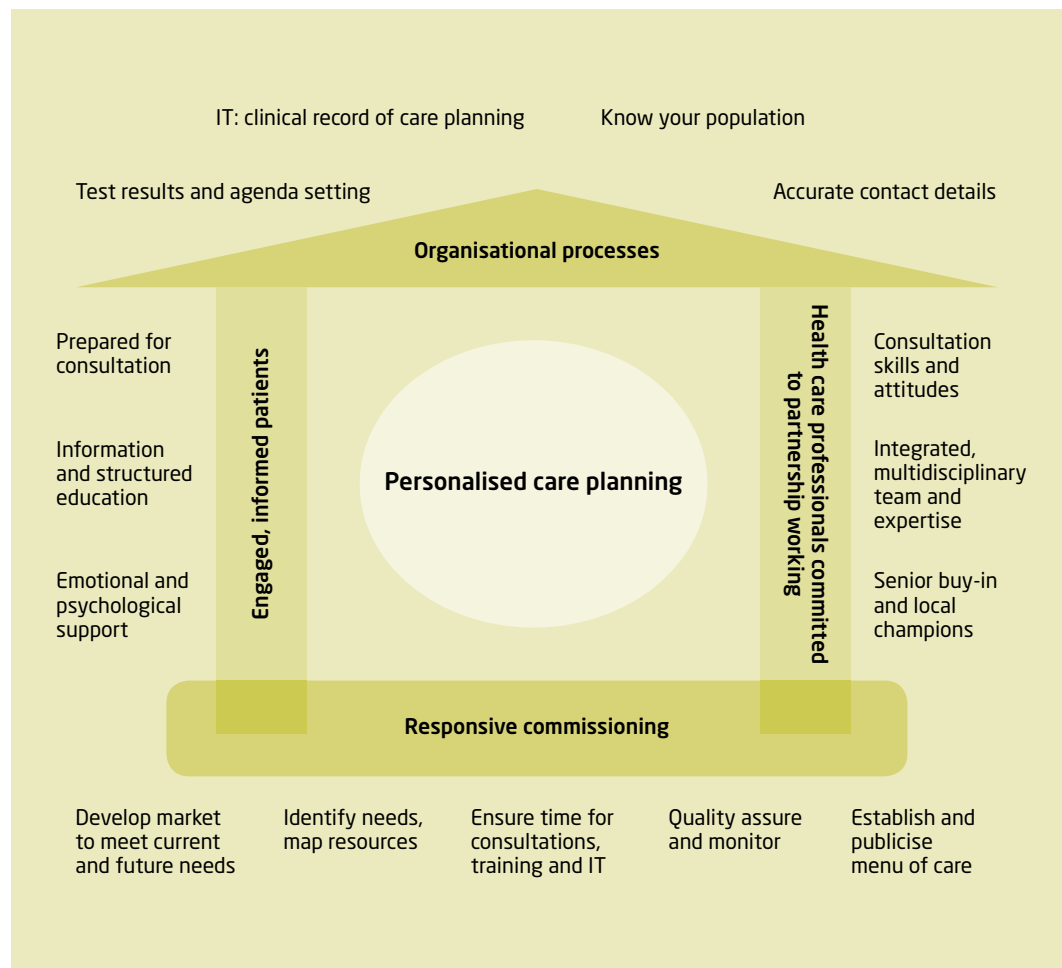
Putting all the components together

Local providers and commissioners need to ensure that all the components of the house of care are in place if the desired impacts are to be achieved (Figure 6). This will involve:

- acknowledging the philosophy and principles of systematic support for self-management (the driver of the delivery system)
- identifying accountable leadership
- identifying the population involved (risk stratification)
- identifying the capacity of individuals to engage in the necessary processes and supporting them to do so

- identifying the multidisciplinary teams involved and the roles and responsibilities of each team member in order to ensure that care is personalised and co-ordinated
- using available evidence-based and quality-assured training
- identifying robust metrics, data collection methods, analysis and feedback to drive improvement.

Figure 6 Putting all the components of the house of care in place



Overcoming barriers

Few of those we spoke to had managed to assemble all the various components needed for the house of care in one place. While a range of activities are being conducted with enthusiasm, they are often isolated efforts. There are also some national barriers that are preventing progress, for example, problems related to contracts and incentives in primary care, inflexible IT systems and a lack of agreed outcome measures.

It was often the case that where one primary care team was struggling with a particular component, another had found a solution. Ensuring that all components are in place is no easy task; but recognising the need to assemble them all in order to construct the house in its entirety is the key to effective delivery.

The momentum for this new way of working is taking hold across England. Some 3,000 practitioners in 26 communities have begun to introduce aspects of the house of care model via the Year of Care programme – an approach that links attitudes, skills and infrastructure. Systematic community support is generally less well incorporated and the patchy use of metrics, inflexible IT systems and limited ongoing support mean there is still much to do to capitalise on their enthusiasm for this ‘better way of working’.

However, since few sites have adopted the model in full, with all the components in place, we cannot yet be certain that it will deliver the desired results. Studies underline the need for caution before assuming that promising blueprints will reliably produce the expected outcomes. Yet the discussions and sharing of experience at the workshop organised by The King’s Fund generated a great deal of excitement. There was a general consensus among participants that a model that starts and ends with an improved patient–clinician partnership is worth adopting and should now be pursued with more vigour.

The time is therefore ripe for a renewed effort to deliver better care for people with long-term conditions. Patient organisations are calling for a new approach, and financial pressures on the NHS and social care require co-ordinated action to secure better value from limited resources. These pressures are especially acute in primary care, encouraging professionals to seek a different approach. The Department of Health’s [Mandate](#) and the [NHS Outcomes Framework](#) have set out the new direction for health and social care. CCGs now have both the incentive and the opportunity to move this agenda forward.

Change on the scale needed is not easy, especially when the main barriers involve aspects of organisational culture. Implementing the house of care challenges the way the workforce is developed and how training is organised and quality assured. There is a need not just for better metrics but for better use of those metrics. Current IT systems cannot cope with issues such as recording patients’ issues and goals, printing off personalised letters and care plans or gathering real-time feedback for clinicians.

Multi-morbidity – especially where people have complex mental as well as physical health problems – poses additional challenges, as the primary care [QOF](#), most clinical guidelines, and the most common IT systems and datasets are all structured around single conditions.

However, none of these problems is insurmountable. Co-ordinated action at both local and national levels could do much to overcome them.

The way forward

The preparation and discussion around The King’s Fund workshop provided a rich source of thinking to underpin a new strategy for helping people with long-term conditions. Participants focused on what needed to be put in place to make this a reality. Three main needs emerged: a clear narrative describing care planning and the infrastructure needed to support it (a gap that we hope has now been filled by this report); a ‘hub’ for disseminating this narrative, providing a source of support and co-ordinating activities; and a ‘coalition of the determined’, each contributing from their own perspective, building on the pledges they made at the event and ensuring that their activities are aligned with and support the joint endeavour.

Workshop participants and interviewees suggested various actions that could be taken by organisations at different levels in the system to help embed this way of working.

NHS England should:

- adopt and promote a compelling narrative so that everyone understands what is expected of them in respect of care planning for people with long-term conditions
- assist a national support unit or hub to help local sites, particularly helping them tackle any barriers they encounter
- ensure that the GP contract is aligned to support this approach and that its incentives reflect the importance of care planning
- model the care planning approach through specialist commissioning
- develop and test funding mechanisms that facilitate co-ordinated care, including the use of non-traditional services such as those provided by community or third sector organisations
- develop a set of measures that can be used across the system, including patient reported experience measures (PREMs) and patient reported outcome measures (PROMs), to be used for improvement as well as quality assurance
- liaise with suppliers of GP computer systems to encourage the development of care planning modules integrated into the main clinical record
- liaise with IT companies and others to encourage system interoperability to enable data-sharing across service boundaries and the inclusion of self-management capabilities and social care data in risk stratification
- be ready to de-commission poor-quality primary care services.

Clinical commissioning groups and primary care teams should:

- use the resources and concepts that the delivery system provides to systematically re-design services and build their own house of care, actively working with local partners to share risks over the medium as well as the short term
- work with NHS England to help primary care shift from the current episodic approach to caring for patients with long-term conditions to an approach that is more anticipatory and planned
- be ready to challenge negative attitudes and encourage awareness of new ways of working in partnership with patients
- monitor the extent to which patients are engaged in decisions, have personalised care plans, and receive co-ordinated services and appropriate support for self-management
- ensure that good-quality training courses in care planning and self-management support are available and that staff are encouraged to attend them, with locum cover and back-fill funding when necessary
- recognise that provision of occasional ad hoc workshops or courses, however good, will not be sufficient to achieve measurable changes in practice; a more strategic approach is required
- agree common goals for care planning, as well as outcome measures, and provide analytical support and feedback
- actively work with health and wellbeing boards to ensure that a portfolio of commissioned and non-commissioned community or peer support is available and/or signposted to patients when necessary

- develop and make available directories of community services and other non-traditional self-care support services
- ensure that patient records are in good order and contact details are up to date
- work to ensure that local electronic health records are fit for care planning and share information with other organisations, including those in the community
- allow patients to access their electronic medical records and develop shared records for care planning.

Health Education England should:

- produce a new workforce development strategy for long-term conditions that is aligned with the components of the house of care and supports care planning
- ensure that the core competencies for care planning are related to service needs rather than professional roles
- ensure that primary care and the primary care workforce strategy are adequately represented in local education and training boards
- work with Royal Colleges, the General Medical Council, the Nursing and Midwifery Council, the Health and Care Professions Council and other standard-setting groups to ensure that collaborative care planning is a key component and is reflected in curricula
- work with Royal Colleges and specialist societies to strengthen clinical leadership in relation to care planning and systematic support for people with long-term conditions
- develop a quality assurance framework for training courses to support people with long-term conditions and work with training bodies to ensure that these are incorporated in relevant programmes
- develop the standards and quality criteria for training courses in shared decision-making, care planning and self-management support
- work with Royal Colleges and specialist societies to strengthen medical leadership in relation to personalised care planning for people with long-term conditions.

The Department of Health should:

- adopt and promote a compelling narrative so that all health and care professionals and organisations understand what is expected of them with respect to care planning for people with long-term conditions
- encourage the National Institute for Health Research, universities, Collaborations for Leadership in Applied Health Research and Care, Academic Health Science Networks and policy research centres to carry out relevant research into the effects of care planning, including evaluation of pilot projects.

Conclusion

The house of care model we have described here is a deliberate simplification of a complex delivery system with primary care as its cornerstone and personalised care planning at its heart, underpinned by the solid foundation of responsive commissioning. Each of the individual components of the model is being implemented in various primary and secondary care sites across England. Putting all the components in place at the same time has proved challenging, but everyone we spoke to was confident that a fully functioning house of care is perfectly feasible within the NHS right now, without needing radical system reform.

However, the projects we have described constitute bold initiatives led by pioneering individuals who are willing to take risks. It is unrealistic to rely on these leaders to make change happen across the board. It is high time that the barriers to implementing the full house of care model were swept away, making it much easier for everyone to do it – not just the heroes and heroines. The prize of well co-ordinated personalised care for everyone who needs it is within our grasp. Getting there will require a coalition of the determined, plus strong support at national as well as local levels.

References

- Bardsley M, Steventon A, Smith J, Dixon J (2013). *Evaluating Integrated and Community-Based Care: How do we know what works?* London: Nuffield Trust.
- Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B (2012). 'Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study'. *The Lancet*, vol 380, no 9836, pp 37–43.
- Battersby MW, Ask A, Reece MM, Markwick MJ, Collins JP (2003). 'The Partners in Health scale: the development and psychometric properties of a generic assessment scale for chronic condition self-management'. *Australian Journal of Primary Health*, vol 9, no 3, pp 41–52.
- Bucknall CE, Miller G, Lloyd SM, Cleland J, McCluskey S, Cotton M, Stevenson R, Cotton P, McConnachie A (2012). 'Glasgow supported self-management trial (GSuST) for patients with moderate to severe COPD: randomised controlled trial'. *British Medical Journal*, vol 344, e1060.
- Burt J, Roland M, Paddison C, Reeves D, Campbell J, Abel G, Bower P (2012). 'Prevalence and benefits of care plans and care planning for people with long-term conditions in England'. *Journal of Health Services Research & Policy*, vol 17, suppl 1, pp 64–71.
- Corbin J, Strauss A (1988). *Unending Work and Care: Managing chronic illness at home*. California: Jossey-Bass.
- Coulter A, Collins A (2011). *Making Shared Decision-Making a Reality: No decision about me, without me*. London: The King's Fund.
- Cramm JM, Strating MM, de Vreede PL, Steverink N, Nieboer AP (2012). 'Validation of the self-management ability scale (SMAS) and development and validation of a shorter scale (SMAS-S) among older patients shortly after hospitalisation'. *Health and Quality of Life Outcomes*, vol 10, no 9.
- Department of Health (2013). *Individuals in Receipt of NHS Continuing Healthcare* [online]. Health and Social Care Information Centre. Available at: www.gov.uk/government/publications/nhs-continuing-healthcare (accessed on 29 August 2013).

- Department of Health (2012a). *Long Term Conditions Compendium of Information*, 3rd ed. London: Department of Health. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_134486.pdf (accessed on 28 August 2013).
- Department of Health (2012b). *The Mandate: A mandate from the government to the NHS Commissioning Board: April 2013 to March 2015*. London: Department of Health. Available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/213131/mandate.pdf (accessed on 28 August 2013).
- Diabetes UK (2011). 'Thanks for the Petunias': A guide to developing and commissioning non-traditional providers to support the self management of people with long term conditions. London: Diabetes UK.
- Diabetes UK, Department of Health, The Health Foundation, NHS Diabetes (2011). *Year of Care: Report of findings from the pilot programme*. London: Diabetes UK, Department of Health, The Health Foundation, NHS Diabetes.
- Epping-Jordan JE, Pruitt SD, Bengoa R, Wagner EH (2004). 'Improving the quality of health care for chronic conditions'. *Quality and Safety in Health Care*, vol 13, no 4, pp 299–305.
- Fan VS, Gaziano JM, Lew R, Bourbeau J, Adams SG, Leatherman S, *et al* (2012). 'A comprehensive care management program to prevent chronic obstructive pulmonary disease hospitalizations: a randomized, controlled trial'. *Annals of Internal Medicine*, vol 156, no 10, pp 673–83.
- Forder J, Jones K, Glendinning C, Caiels J, Welch E, Baxter K, Davidson J, Windle K, Irvine A, King D, Dolan P (2012). *Evaluation of the Personal Health Budget Pilot Programme*. Discussion Paper 2840_2. London: Department of Health.
- Greene J, Hibbard JH (2012). 'Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes'. *Journal of General Internal Medicine*, vol 27, no 5, pp 520–6.
- Hibbard JH, Greene J (2013). 'What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs'. *Health Affairs (Millwood)*, vol 32, no 2, pp 207–14.
- Hibbard JH, Mahoney ER, Stockard J, Tusler M (2005). 'Development and testing of a short form of the patient activation measure'. *Health Services Research*, vol 40, no 6, pt 1, pp 1918–30.
- Horne M, Khan H, Corrigan P (2013). *People Powered Health: Health for people, by people and with people*. London: Nesta. Available at: www.nesta.org.uk/library/documents/PPHforpplbyppl2.pdf (accessed on 29 August 2013).
- Howie JG, Heaney DJ, Maxwell M, Walker JJ (1998). 'A comparison of a Patient Enablement Instrument (PEI) against two established satisfaction scales as an outcome measure of primary care consultations'. *Family Practice*, vol 15, no 2, pp 165–71.
- Kennedy A, Bower P, Reeves D, Blakeman T, Bowen R, Chew-Graham C, *et al* (2013). 'Implementation of self management support for long term conditions in routine primary care settings: cluster randomised controlled trial'. *British Medical Journal*, vol 346, f2882.
- McShane M, Mitchell EW (2013). 'Put individuals at the centre of care'. *Health Service Journal*, 9 July, pp 26–7.

- Mercer SW, Maxwell M, Heaney D, Watt GC (2004). 'The consultation and relational empathy (CARE) measure: development and preliminary validation and reliability of an empathy-based consultation process measure'. *Family Practice*, vol 21, no 6, pp 699–705.
- Morioka S, Farrington S, Hope P, Brett K (2013). *The Business Case for People Powered Health*. London: Nesta, The Innovation Unit, Private Public Ltd. Available at: www.nesta.org.uk/areas_of_work/public_services_lab/health_and_ageing/people_powered_health/assets/features/the_business_case_for_people_powered_health (accessed on 29 August 2013).
- National Voices (2013). *A Narrative for Person-Centred Coordinated Care*. London: National Voices. Available at: www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf (accessed on 2 September 2013).
- Newbould J, Burt J, Bower P, Blakeman T, Kennedy A, Rogers A, Roland M (2012). 'Experiences of care planning in England: interviews with patients with long term conditions'. *BMC Family Practice*, vol 13, no 1, p 71.
- Nuffield Trust, Imperial College London (2013). *Evaluation of the First Year of the Inner North West London Integrated Care Pilot*. London: Nuffield Trust.
- Nuffield Trust, The King's Fund (2013). 'Developing a National Strategy for the Promotion of Integrated Care'. Nuffield Trust website. Available at: <http://www.nuffieldtrust.org.uk/publications/integrated-care-patients-populations-improving-outcomes> (accessed on 5 September 2013).
- Powell RP, Powell H, Baker L, Greco M (2009). 'Patient partnership in care: a new instrument for measuring patient–professional partnership in the treatment of long-term conditions'. *Journal of Management & Marketing in Healthcare*, vol 2, no 4, pp 325–42.
- Richmond Group of Charities, The King's Fund (2012). *From Vision to Action: Making patient-centred care a reality*. London: The King's Fund. Available at: www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Richmond-group-from-vision-to-action-april-2012-1.pdf (accessed on 2 September 2013).
- Roland M, Abel G (2012). 'Reducing emergency admissions: are we on the right track?'. *British Medical Journal*, vol 345, e6017.
- Roland M, Lewis R, Steventon A, Abel G, Adams J, Bardsley M, Brereton L, Chitnis X, Conklin A, Staetsky L, Tunkel S, Ling T (2012). 'Case management for at-risk elderly patients in the English integrated care pilots: observational study of staff and patient experience and secondary care utilisation'. *International Journal of Integrated Care*, vol 12, e130.
- Schmitt diel J, Mosen DM, Glasgow RE, Hibbard J, Remmers C, Bellows J (2008). 'Patient Assessment of Chronic Illness Care (PACIC) and improved patient-centered outcomes for chronic conditions'. *Journal of General Internal Medicine*, vol 23, no 1, pp 77–80.
- Steventon A, Bardsley M, Billings J, Dixon J, Doll H, Hirani S, Cartwright M, Rixon L, Knapp M, Henderson C, Rogers A, Fitzpatrick R, Hendy J, Newman S (2012). 'Effect of telehealth on use of secondary care and mortality: findings from the Whole System Demonstrator cluster randomised trial'. *British Medical Journal*, vol 344, e3874.
- Wagner EH (1998). 'Chronic disease management: what will it take to improve care for chronic illness?' *Effective Clinical Practice*, vol 1, no 1, pp 2–4.

Appendix: Workshop participants and interviewees

Name	Job title	Organisation	Interviewed
Sponsors			
Dr Anna Dixon	Director of Policy	The King's Fund	
Dr Martin McShane	Director, Improving the quality of life for people with long-term conditions	NHS England	
Attended event			
Michael Adamson	Managing Director, Operations	British Red Cross	
Alison Austin	Head, Personal Health Budget Team	Department of Health	Yes
Elaine Bayliss	Programme Manager, National End of Life Care Programme	NHS Improvement	
Laura Boothman	Policy Manager	Arthritis Research UK	
Amanda Cheesley	Long Term Conditions Adviser	Royal College of Nursing (RCN)	
Dr Alf Collins	Clinical Associate	The Health Foundation	
Sarah Collis	Director	Self Help Nottingham	Yes
Prof Paul Corrigan	Management Consultant	Paul Corrigan	
Dr Angela Coulter	Visiting Fellow	The King's Fund	
Ciaran Devane	Chief Executive	Macmillan Cancer Support	
Dr Matthew Dolman	Chair, Clinical Operations Group	Somerset CCG	
Prof Chris Drinkwater	Professor	NHS Alliance	Yes
Prof Ray Fitzpatrick	Professor of Public Health and Primary Care	University of Oxford	
Prof Judith Hibbard	International Visiting Fellow	The King's Fund	
Dr Isabel Hodgkinson	RCGP Lead for Care Planning	The Tredgar Practice	Yes
Ruthe Isden	Public Services Programme Manager	Age UK	
Halima Khan	Director, Public Services Lab	Nesta	
Dr James Kingsland	National Clinical Lead	National Clinical Commissioning Network	
Dr Steven Laitner	National Clinical Lead for Shared Decision Making	Department of Health	
Nicola Levitt	Head of Strategy	Health Education England	
Dr Nick Lewis-Barned	Consultant Physician, RCP SDM Clinical Fellow	Royal College of Physicians (RCP)	Yes
Dr Johnny Marshall	Associate Director	NHS Confederation	
Prof Nigel Mathers	Vice Chair	Royal College of General Practitioners (RCGP)	Yes
Dr Ed Mitchell	Clinical Fellow	NHS England	
Dr Penny Newman	GP and Director of Integration	Colchester Hospital University NHS Foundation Trust	
Dr Alan Nye	Director	Pennine MSK Partnership Ltd	Yes
Luke O'Shea	Head of Patient Participation	NHS England	
Dr Linda Patterson	Clinical Vice President	Royal College of Physicians	
Jim Phillips	Director	Quality Institute for Self Management Education & Training (QISMET)	Yes
Dr Joanne Protheroe	Senior Lecturer in General Practice	Keele University	
Mat Rawsthorne	Fellow	Institute of Mental Health	
Don Redding	Policy Director	National Voices	
Sondra Roberto	Policy Manager	The Health Foundation	
Dr Sue Roberts	Chair, Year of Care Partnerships	Northumbria Healthcare Foundation Trust	
Lara Sonola	Researcher	The King's Fund	
Susan Summers	Head of Long Term Conditions	NHS England	
Prof Richard Thomson	Professor of Epidemiology and Public Health	Newcastle University	Yes
Anne Tidmarsh	Director of Older People and People with Disability	Kent County Council	Yes
Bridget Warr	Chief Executive	UK Homecare Association Limited (UKHCA)	
Jo Webber	Interim Director of Policy	NHS Confederation	
Jacque White	Deputy Domain Director (Long-Term Conditions)	NHS England	
Dr Nina Wilson	National Clinical Fellow	NHS England	
Interviewed only			
Dr Hugh Reeve	Clinical Chair	Cumbria CCG	Yes

About the authors

Angela Coulter is a health policy analyst and health services researcher who specialises in patient and public involvement in health care. She is Director of Global Initiatives at the Informed Medical Decisions Foundation and a senior research scientist at the Nuffield Department of Population Health, University of Oxford. Angela holds honorary fellowships at the Faculty of Public Health, the Royal College of General Practitioners and The King's Fund, and she is a trustee of National Voices, a coalition of patient organisations. She has published more than 300 research papers and reports and several books, including *Engaging Patients in Healthcare*, Open University Press, 2011.

Sue Roberts is Chair of Year of Care Partnerships at Northumbria Healthcare Foundation Trust. Previously she was National Clinical Director for Diabetes and a consultant physician for 30 years in acute and long-term condition specialties. Sue pioneered structured and integrated diabetes care and prevention programmes for cardiovascular disease across North Tyneside and Northumberland and has designed services in acute medicine, gastroenterology, nutrition and health complications of alcohol. Sue helped to introduce rigorously evaluated structured education programmes for people with diabetes into the UK. She advises on the commissioning and delivery of patient-centred services for people with long-term conditions and the mainstream change that is needed to support and embed this. She is an honorary fellow of the Royal College of General Practitioners.

Anna Dixon is Director of Strategy and Quality and Chief Analyst at the Department of Health England.

Anna began her career with the World Health Organization working as a research officer for the European Observatory on Health Care Systems. In 2003–4 she worked as a policy analyst in the Department of Health Strategy Unit where she focused on a range of issues including choice, global health and public health. She has undertaken consultancy work for a range of clients including OECD, Monitor, Care Quality Commission, and the Treasury as well as advising numerous Ministries of Health including Hong Kong, Portugal and the UK government.

Anna was previously Lecturer in European Health Policy at the London School of Economics and Political Science. In 2005–6 she was awarded a Harkness Fellowship in Health Policy by the Commonwealth Fund of New York. Before joining the Department of Health, Anna was Director of Policy at The King's Fund where she led work on health system reforms, regulation, patient choice, self-management of long-term conditions and the future of health and social care in England.

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Co-ordinated care for people with complex chronic conditions

Key lessons and markers
for success

Authors

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Key messages

Based on a comparative analysis of five UK-based case studies of care co-ordination programmes for people with long-term and complex chronic conditions, this report examines key lessons and markers for success in the ‘how’ of care co-ordination that might be transferable to different contexts and settings.

In terms of the process of care co-ordination, the following factors appear to be important design features.

- At a *personal* level, a holistic focus that supports service users and carers to become more functional, independent and resilient, and to live well by managing their conditions in the home environment, is preferable to a purely clinical focus on managing or treating medical symptoms.
- At a *clinical and service* level, it is important to encourage multiple referrals into a single entry point where care co-ordination can be supported. Named care co-ordinators are needed to support the process of care co-ordination by providing a source of personal continuity to patients and carers as well as enabling access to care through multidisciplinary teams.
- At a *community* level, the role of members of the local community should be seen as integral to the care-giving process. Building community awareness and trust promotes legitimacy and engagement, which can provide an essential resource within care co-ordination programmes.
- At a *functional* level, effective communication between members of the multidisciplinary team is essential. There is a need for shared electronic health records to support the process, but a ‘high-touch, low-tech’ approach has value in promoting face-to-face communication, fostering collaboration and enabling meaningful conversations about the needs of patients with complex needs.
- At an *organisational* level, effective targeting of service users is required to prioritise care provision. Programmes of care co-ordination need to be localised so that they concentrate on specific communities and neighbourhoods. Local leadership and long-term commitment from commissioners and providers is important to establish a shared vision and to challenge silo-based thinking.
- At a *system* level, integrated health and social care commissioning can support longer-term strategies and provide a greater degree of stability. A political narrative that supports person-centred care co-ordination provides credibility when developing new ways of working.

When implementing care co-ordination in different contexts and settings, the following key lessons can be drawn.

- There is a chronic lack of evaluation and measurement on which to judge the performance of care co-ordination programmes. This is a fundamental weakness; far greater attention is required to measure, evaluate, compare and reflect on performance.

- It can take some years for programmes of care co-ordination to mature – and to build the necessary legitimacy and capability for them to become accepted by both professionals and patients.
- Successful approaches to care co-ordination have highly context-specific case histories, and models of care cannot simply be transported ‘en bloc’ from one setting to another. Understanding one’s own local context is the key to learning lessons and successfully transferring approaches from other programmes of care.
- Care co-ordination programmes appear to flourish at the neighbourhood level where the benefits of engagement with local communities sit alongside the need to have close working relationships within multidisciplinary care teams dealing with manageable caseloads.
- There is potential to scale up operations through building a number of locality-based approaches to care under the direction of an umbrella organisation. Such an approach might have a bigger impact in improving cost-effectiveness, which otherwise appears to be limited.
- Care co-ordination needs to be taken forward primarily as a quality improvement strategy rather than one specifically aimed at reducing costs.
- Across all of the five case study programmes, the apparent disengagement of general practitioners (GPs) was a cause for concern; it made information exchange more problematic and limited the ability to bring their general knowledge of the patient/family into discussions about care.
- Weak links with secondary care need to be addressed to ensure better quality transitions from hospital to home, to reduce readmission rates and secure faster access to specialist knowledge in the care process.
- Models of care co-ordination are likely to be more effective when they operate as ‘fully integrated’ provider teams with a degree of operational autonomy.
- Without full alignment across the political, regulatory, organisational and professional spectrum towards the goals of co-ordinated care, too much reliance is placed on local leaders to make change happen.

About the authors

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Prior to his academic career, Dennis held several senior leadership positions at a teaching nursing home, continuum of care health system, health maintenance organisation and hospital. He is well-known for his pioneering work as CEO of Elderplan Social HMO pilot.

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Preface

Co-ordination of care for people with complex chronic illness is a global challenge. Driven by broad shifts in demographics and disease status, age-related chronic and complex medical conditions account for the largest share of health care budgets internationally (Epping-Jordan *et al* 2004). However, people living with multiple health and social care needs often experience a highly fragmented service, leading to sub-optimal care experiences, outcomes and costs. To address this, strategies for care co-ordination have been developed in many countries, yet evidence suggests that many such innovations have not achieved their objectives and the failure rate has been high (Goodwin 2011). In particular, there remains a lack of knowledge about how best to apply care co-ordination in practice.

About this report

This report brings together the key findings from a two-year research project funded by Aetna and the Aetna Foundation (The King's Fund 2013). The overall aim of the research was to understand the components of effective strategies that have been used in the United Kingdom to deliver co-ordinated care for people with long-term and complex needs. In addition, the research sought to tease out the key lessons and markers for success to help identify how care co-ordination could be transferred from the UK to the US context.

The research involved an in-depth investigation of five UK-based programmes of care co-ordination for people with complex needs, which were selected on the basis that they had been successful in moving towards meeting the 'Triple Aim' challenge (Institute for Healthcare Improvement 2013) of improved care experiences, better care outcomes and more cost-effective service delivery. This report provides a synthesis of our findings. Separate reports on the experiences and impact of each of the five case study programmes have been published by The King's Fund (Sonola *et al* 2013a, 2013b; Thiel *et al* 2013a, 2013b, 2013c). A summary of the research methods used to select and investigate the five case study sites is provided in Appendix A.

Introduction

What is care co-ordination?

The term ‘care co-ordination’, like ‘integrated care’, does not have a universally recognised definition. For example, it is often used synonymously with ‘case management’, ‘disease management’ or ‘multidisciplinary teams’ (McDonald *et al* 2007). Indeed, the terms ‘co-ordination’ and ‘integration’ are frequently used interchangeably, though the former tends to refer to patient-focused or clinical interventions while the latter focuses on organisational or managerial issues (Kodner 2009). The following definition from the National Coalition on Care Coordination describes the typical components of the approach:

‘Care coordination’ is a person-centered, assessment-based, interdisciplinary approach to integrating health care and social support services in a cost-effective manner in which an individual’s needs and preferences are assessed, a comprehensive care plan is developed, and services are managed and monitored by an evidence-based process which typically involves a designated lead care coordinator.

(National Coalition on Care Coordination 2011)

However, reviews of the concept recognise that care co-ordination may be achieved in many different ways to deliver the common objective of facilitating a more proactive approach to bringing care services together around the needs of service users (McDonald *et al* 2007; Van Houdt *et al* 2013). Hence, care co-ordination consists of a range of strategies that seek to create more integrated and person-centred care across various settings (Hofmarcher *et al* 2007). Broadly speaking, the approach entails making care systems more attentive to the needs of individual patients and ensuring that they get an appropriate package of care that seeks to stabilise their health over long periods and in less costly environments. Care co-ordination, therefore, is particularly relevant to patients with chronic and complex medical conditions who may find it difficult to navigate fragmented health care systems.

The growing importance of care co-ordination in the United Kingdom and the United States

In both the United Kingdom and the United States, despite significantly different systems of care (*see* Table 1), person-centred care co-ordination is now widely recognised as a critical component of privately and publicly funded health care. It has been especially applied in the clinical management of patients with complex and costly conditions whose needs cut across multiple services, providers and settings.

Table 1 outlines the main differences between the structure of the health and social care systems in the United Kingdom (England and Wales only) and the United States. These systems differ between the four countries of the United Kingdom (England, Scotland, Wales and Northern Ireland). There were no case studies in Scotland or Northern Ireland, so these countries have not been included in the table. The table highlights differences between England and Wales where applicable.

Table 1: Comparison of health and social care systems in the United Kingdom and the United States

	United Kingdom (England and Wales)	United States
Funding: health	Taxpayer-funded; private health care insurance is available, but the market is small	Multiple private and public sources, including private insurance, Medicare and Medicaid. Medicare: a social insurance programme for older people and people with disabilities funded through a combination of taxes, premiums and federal government subsidies. Medicaid: means-tested programme jointly run by the federal and state governments targeted at people with low incomes and insufficient means to pay medical bills. Medicaid eligibility and coverage vary from state to state
Funding: social care	Means-tested taxpayer funding with high levels of co-payments and self-funding	In the United States, social care is called long-term care (LTC) services and support. Medicaid is the dominant source of payment for LTC, followed by self-funding and co-payments
Cost to patient: health	Health care: free at the point of service	Health: depends on type of cover. Private: depending on health plan, substantial co-payment and deductibles. Medicare: private insurance to cover co-payment and deductibles. Medicaid: free at the point of service
Cost to patient: social care	<i>England:</i> patient pays full costs if they have assets of £23,500 or more; costs highly variable depending on need and location, and can be substantial. Introduction of higher self-funding threshold in 2016 will make more people eligible for free social care <i>Wales:</i> maximum co-payment of £50 per week	LTC: if Medicaid-eligible after meeting income and asset requirements (which vary by state), free at point of service
Commissioning and care provision: health	<i>England:</i> 211 clinical commissioning groups (CCGs) commission services from National Health Service (NHS), third sector and independent sector providers. Majority of services provided by NHS <i>Wales:</i> no internal market, regional health boards set strategies; no commissioning/provider split	There is no commissioning process in the United States <i>per se</i> Insurance companies, the state and the federal government enter into direct contracts with private, third sector and public providers The federal government and the states also enter into direct contracts under Medicare and Medicaid respectively with managed care plans and case management and other co-ordinated care programmes. Reimbursement arrangements in the private market vary by insurer and insurance product
Commissioning and care provision: social care	Assessments carried out by social workers (free); occupational therapists and physiotherapists employed by local authorities; personal care provided largely by private agencies commissioned by local authorities	LTC: see above. Depending on the type of LTC programme or service and state, assessments carried out by state or county social workers and/or nurses or by employees of provider organisations
Role of general practitioner (GP)	GP practices are independent businesses commissioned by the NHS as gatekeepers to secondary/specialist care; more than 90% of the population are registered with a GP. GPs operate increasingly in partnerships such as networks or federations. Other organisational forms are slowly emerging following the health and social care reforms in 2012. Patients can choose a GP in a geographically defined area near to their home	Primary care in the United States is provided by general internists, family physicians and nurse practitioners - ie, primary care providers (PCPs). Primary care provision can take a variety of forms - eg, independent practice association, health maintenance organisation or medical home Regardless of insurance cover or delivery arrangement, patient is generally free to choose their own PCP
Community care	Highly developed, with frequent co-location of community care staff in GP practices; low staffing levels may be a risk as levels of health care provision in the community increase	Highly developed LTC resources with major emphasis on providing home and community-based services (the equivalent of social care in the United States), especially in state Medicaid programmes. Links with primary care can be problematic in the fee-for-service sector, but strong connections in existing and emerging managed care/co-ordinated care/integrated care models

Table 1: (continued)

	United Kingdom (England and Wales)	United States
Sustainability issues: health	Increasing demand on all health services due to ageing population; current increase in demand on emergency services; £20 billion savings to be made by 2015, expectation of austerity/flat funding beyond this point	Increasing demand on all health services largely due to ageing population and chronic illness. Federal and state concerns about maintaining control over rising costs. The financial impact of the Patient Protection and Affordable Care Act 2010 is a major source of uncertainty with regard to sustainability
Sustainability issues: social care	Local authorities required to make large savings, roll-back of services observed in all five case study sites	LTC: see above
Policy drivers	Strong drive to improve vertical and horizontal integration; health reforms could see new providers entering the market in future	The Patient Protection and Affordable Care Act, signed into law in 2010, put in place important reforms of the US system; major emphasis placed on accountable care organisations and other integrated care models, which are taking centre stage in public and private markets

In the United Kingdom, case management and care co-ordination have become well established and have typically been provided through multidisciplinary and community-based health and social care teams, working to improve care post-discharge from hospital and/or to avoid hospitalisations by focusing on ‘at-risk’ individuals in the community (Ross *et al* 2011). While the approach has improved the experiences of users and carers alike, as well as enabling more cost-effective care in some localities, evidence for the effectiveness of such strategies remains mixed and limited; success appears to be highly dependent on the way in which care co-ordination is implemented locally (Curry and Ham 2010; Roland *et al* 2012).

In the United States, co-ordinated care arrangements are largely found in integrated delivery systems (eg, Kaiser Permanente), health maintenance organisations (HMOs) and other special ‘carve out’ managed care programmes (eg, the Program of All-Inclusive Care for the Elderly (PACE)) operating within a capitated or budgeted environment. Care co-ordination is a prominent feature of programmes supported by Medicare and Medicaid. For example, Medicare Advantage health plans, in which 20 per cent of Medicare beneficiaries are voluntarily enrolled, routinely provide care co-ordination services.¹ Special Needs Plans (SNPs) – a type of Medicare Advantage plan that provides intensively targeted care to ‘special needs individuals’ – are designed to improve care primarily through improved co-ordination and continuity of care.²

In both the United Kingdom and the United States, the need to encourage care co-ordination to tackle the rising demands placed on health systems by ageing populations with complex needs has become central to national strategies. In England, the case for person-centred care co-ordination has moved rapidly up the policy agenda to become a central theme in health and social care reform (Goodwin *et al* 2012). As a result, a shared cross-government commitment – the National Collaborative for Integrated Care and Support – was created in May 2013 with the aim of creating a new culture of co-operation and co-ordination between care sectors. This includes a more ambitious vision for rolling out integrated care ‘at scale and pace’ through ‘whole-system’ approaches promoted by the Department of Health’s integrated care pioneer programme (Ham and Walsh 2013). The governments of Scotland, Wales and Northern Ireland have similarly pursued a range of reforms to support health and social care integration, though analysis

¹ Medicare beneficiaries have the option of receiving their benefits under Medicare Part A (hospital) and Part B (medical) through these private plans as an alternative to the federally administered traditional Medicare programme. Medicare Advantage plans, which are sponsored by for-profit and non-profit insurance and provider organisations, receive a capitated (per enrollee) payment to provide these covered services. The benefit package frequently includes benefits beyond the traditional programme (eg, foot care, optical services, etc) and may require an additional out-of-pocket premium.

² ‘Special needs individuals’ include: institutionalised beneficiaries (ie, nursing home residents); individuals with severe or disabling chronic conditions; and, ‘dual eligibles’ (ie, individuals, usually with complex conditions and needs, who are covered by both Medicare and Medicaid).

suggests that their focus on organisational restructuring has not necessarily led to the successful deployment of effective care co-ordination strategies at the clinical and service level (Ham *et al* 2013).

In the United States, two key national initiatives have been developed in recent years to promote care co-ordination: the 'medical home' and the 'accountable care organisation' (ACO). The medical home model is a physician-led, team-based comprehensive primary care model in which care co-ordination and innovative payment methods are designed to enhance quality outcomes and cost-effectiveness; medical homes are being developed in both the private and the public sectors. ACOs, on the other hand, are networks of physicians, hospitals and other health care providers that voluntarily come together and are held accountable for the quality and cost of the entire continuum of care delivered to a group of patients. While ACOs are being developed in the private sector, they are also now a key feature of the Medicare programme, with more than 220 Medicare ACOs having been established as of January 2013, potentially covering 4 million enrollees. Likewise, many states have shown an interest in the potential of the ACO model to co-ordinate care for Medicaid recipients.

At a national level, the Patient Protection and Affordable Care Act 2010 (ACA) in the United States has encouraged greater emphasis on care co-ordination, which has become one of six priorities in the recently adopted US National Strategy for Quality Improvement in Health Care (Agency for Healthcare Research and Quality 2012). Care co-ordination and the companion strategies were selected because of their potential to improve health outcomes and increase the effectiveness of care for all Americans. Created under the ACA, the strategy will guide local, state and national efforts to promote better health and quality of care for Americans.

Understanding the nature and benefits of care co-ordination: the need for closer investigation

This research involved a non-systematic review of the literature on care co-ordination for people with complex needs in order to develop some *a priori* criteria to act as a frame of reference for our investigations and findings. The evidence from this review suggested that comprehensive, systems-based solutions to care co-ordination have the potential to improve collaboration within and between various parts of the health care enterprise; they can encourage patients to become more proactive in the management of their own care, and so enable the delivery of better quality services (Devers and Berenson 2009; Ham 2010). Successful approaches to care co-ordination were found to contain a range of key characteristics (*see box opposite*), yet the lack of evaluation in this area means there is scant evidence to support a positive association between better care co-ordination and improved patient experiences, care outcomes and financial efficiencies (Øvretveit 2011). This is particularly true for people with complex long-term medical conditions and multiple needs (Bodenheimer 2008).

Characteristics of successful approaches to care co-ordination

System level

- Universal coverage or an enrolled population with care free at point of use
- Primary/community care-led
- Emphasis on chronic and long-term care
- Emphasis on population health management
- Alignment of regulatory frameworks with goals of integrated care
- Funding/payment flexibilities to promote integrated care
- Workforce educated and skilled in chronic care, teamwork (joint working) and care co-ordination

Organisational level

- Strong leadership (clinical and managerial)
- Common values and a shared mission
- Aligned financial and governance structures
- Integrated electronic health records
- Responsibility for a defined population or service
- A focus on continuous quality measurement and improvement

Clinical and professional integration

- Population management
- Case finding and use of risk stratification
- Standardised diagnostic and eligibility criteria
- Comprehensive joint assessments
- Joint care planning
- Holistic focus, not disease-based
- Single or shared clinical records
- Decision support tools such as care guidelines and protocols
- Technologies that support continuous and remote patient monitoring

Service integration

- Assisted living/care support in home
- Single point of entry
- Care co-ordination and care co-ordinators
- Case management
- Medications management
- Centralised information, referral and intake
- Multidisciplinary teamwork
- Inter-professional networks
- Shared accountability for care
- Co-location of services
- Discharge/transfer agreements to manage care transitions
- Supported self-care

Sources: Bodenheimer 2008; Coleman *et al* 2009; Curry and Ham 2010; Goodwin *et al* 2010; Ham 2010; Hofmarcher *et al* 2007; Kodner 2009; McDonald *et al* 2007; Øvretveit 2011; Powell Davies *et al* 2006; Smith *et al* 2012; Tsai *et al* 2005

The nature of the evidence in support of effective care co-ordination provides a clear message that systemic and organisational changes alone are unlikely to be sufficient to drive greater care co-ordination at a clinical and service level, even if they provide a supportive framework (Ham *et al* 2013). As the box above suggests, however, there are a range of tools and strategies that may be deployed at the interface between care providers and service users. In practice, it appears that multi-component approaches have more success in meeting the goals of care co-ordination than those that rely on a single or more limited set of delivery strategies (Powell Davies *et al* 2006), yet the evidence for ‘how to’ deliver better care co-ordination remains relatively rare (Curry and Ham 2010). Hence, there is a general lack of knowledge about how best to apply (and combine) the various strategies and approaches to care co-ordination in practice.

Overview of the five care co-ordination programmes

In June 2012, with the support of an international panel of experts, The King's Fund selected five case study programmes from across the United Kingdom that had developed a track record in delivering effective care co-ordination for people with chronic or medically complex needs in primary and community care settings. Here, we provide a summary of the nature of each of these five programmes.

Midhurst Macmillan Community Specialist Palliative Care Service (England)

The Midhurst Macmillan service is a community-based, consultant-led, specialist palliative care programme in West Sussex, England, which covers approximately 150,000 people in a largely rural area across three counties. It is jointly funded by the National Health Service (NHS) and Macmillan Cancer Support, with a budget of around £1.2 million per year. The service enables patients with complex needs who are nearing the end of their lives to be cared for at home, and allows them to die in the place of their choosing. The Midhurst service caters for approximately one-quarter of all people needing end-of-life care in the area. Most patients on the caseload have been diagnosed with cancer, although there are an increasing number of referrals for patients with other conditions, including dementia and heart failure.

The service is run by a multidisciplinary team of nurses and palliative care consultants, occupational therapists and physiotherapists, as well as a large group of volunteers. Six staff – all clinical nurse specialists – act as care co-ordinators for patients. They are part of the multidisciplinary team and work in close co-operation with other care providers in the local area to provide palliative care in people's own homes. Other providers include general practitioners (GPs), district nurses, continuing care teams, and volunteers who are recruited and managed by Macmillan Cancer Support (Thiel *et al* 2013a).

Oxleas Advanced Dementia Service (England)

The Oxleas Advanced Dementia Service provides palliative care and support to enable people with advanced dementia to be cared for at home until their death. It covers the boroughs of Bexley, Bromley and Greenwich, in south London. Eligible patients must have a diagnosis of moderate to severe advanced dementia, with a range of complex mental and physical co-morbidities requiring social care input. A carer (usually a family member) must also be able and willing to care for them at home. Patients tend to be in the last year of their lives, with an average age of 75.

The service is led by an old age psychiatrist, with care co-ordination provided by an advanced practice nurse, community psychiatric nurse or a community matron who specialises in neurology, alongside a dementia social worker. The team has a specific focus on supporting carers to provide palliative care; it works closely with other care professionals, including occupational therapists, physiotherapists, community mental health teams and GPs (Sonola *et al* 2013a).

The Sandwell Esteem Team (England)

The Sandwell Esteem team, based in the West Midlands, is a holistic primary and community care-based approach designed to improve people's social, mental and physical health and wellbeing. The team provides care co-ordination for patients with minor to moderate mental health problems, co-morbidities and complex social needs in a community characterised by high levels of poverty and ill health, both physical and mental. The key aim is to prevent deterioration and admission to secondary care services. The team aims to empower patients to take control of their own lives by offering guided therapies and tools for self-help, as well as helping patients address their social problems by referring them to social and voluntary sector services such as debt advice agencies, abuse counselling services or housing agencies.

The team consists of care co-ordinators (link workers) and is managed by a clinical co-ordinator and support manager. It targets people on the severe mental illness (SMI) register and receives referrals from secondary, primary and community care organisations as well as social care and probation services. Patients can also self-refer. After an initial pilot phase of 18 months with assessments on a case-by-case basis, the service has begun to develop clear and binding referral criteria (Thiel *et al* 2013c).

Community virtual wards in south Devon and Torbay (England)

The community virtual wards based in GP practices in South Devon and Torbay CCG use a predictive risk model to identify patients at risk of admission to hospital, and proactively manage them through community-based multidisciplinary teams. Patients are admitted to the virtual wards on the basis of their risk score combined with assessments made by clinical staff familiar with their case. One of these clinicians also takes on the role of care co-ordinator. Patients are typically frail older people and/or those living with multiple long-term conditions and co-morbidities. During monthly team meetings attended by GPs, community and mental health staff, social workers and voluntary sector representatives, patients' level of risk is discussed and actions are proposed based on their physical and social care needs. The multidisciplinary teams also work with emergency and out-of-hours services to prevent unnecessary admissions to hospital. Co-ordination with the secondary sector and discharge liaison teams seeks to ensure that patients who are admitted to hospital can be discharged quickly back to the community (Sonola *et al* 2013b).

Community resource teams in Pembrokeshire (Wales)

Multidisciplinary community resource teams co-ordinate care for people with long-term illnesses, co-morbidities and frailty. The aim is to enable patients to remain in their homes for as long as possible and to avoid unnecessary hospital admissions.

The teams consist of community health care staff, social workers and voluntary sector representatives. There is also input from GPs and specialist nurses, although this varies from team to team. During weekly meetings, team members discuss patients they deem to be at high risk of hospital admission, and a care plan is developed to reduce this risk and improve the patients' health and wellbeing. Typically, the team member presenting the case will act as care co-ordinator. Patients can also be referred by a professional help desk, which accepts calls from individuals as well as from social workers and GPs. All of the teams have relationships with the secondary and acute sector to co-ordinate care planning when people are discharged from hospital into the community (Thiel *et al* 2013b).

Table 2: A comparison of the five programmes providing co-ordinated care in the United Kingdom

	Midhurst Macmillan Palliative Care Service	Sandwell Esteem Team	Oxleas Advanced Dementia Service	South Devon and Torbay virtual wards	Pembrokeshire community resource teams
General description	Consultant-led, community-based palliative care provision for terminally ill patients in their homes	Community-based specialist mental health and wellbeing services for people with mild to moderate mental health problems	Consultant-led, community-based home care for patients with advanced dementia	Community-based multidisciplinary teams co-ordinating care for older people	Community-based integration of health and social care services for complex case management
Development stage	Well-established service embedded in the local health geography	Completed pilot stage, full integration into borough-wide health and wellbeing hub	Fully developed and embedded in local mental health trust	Virtual ward and predictive risk model fully developed and embedded in south Devon; recent introduction in Torbay (since October 2012). Continued work on predictive risk model to improve accuracy	Four teams have been operating since 2011 as part of a long-term plan to improve horizontal and vertical care co-ordination in Pembrokeshire; teams are still under development and the case study site is a work in progress
Objectives	Enable people to die in the place of their choosing. Avoid unnecessary hospital admissions. Improve quality of life at end of life	Improve health and mental health status of people with complex problems and improve wellbeing in the whole community	Avoid unnecessary accident and emergency (A&E) admissions and discharges to nursing homes; provide patients with care at place of their choosing; relieve carer's stress and improve patient's quality of life	Improve quality of care to users. Simplify access. Reduce number of assessments. Improve referral times. Improve independence. Reduce hospitalisations	Avoid unnecessary A&E admissions for patients with complex needs. Improve discharge from hospital. Improve social and health care co-ordination. Improve independence and quality of life
Dates	2007 to the present	2006 to the present	Greenwich: 2007 to the present; Bexley: 2011 to the present	2010 to the present	2011 to the present
Target population	Patients with complex diseases at the end of their lives in need of palliative care	Patients with complex mental health problems not engaging with secondary services and new cases identified by health practitioners or through self-referral	Patients with advanced stage dementia	Patients with complex health needs in need of intensive care and treatment that can be delivered at home with the right co-ordination	People with complex health and social care needs
Population coverage	All people with complex needs at the end of life in an area covering 19 GP practices (population 150,000)	All people in the Borough of Sandwell (population 309,000)	All people in Greenwich (population 255,500) and Bexley (population 232,800)	All people in GP practices in South Devon and Torbay CCG (population 289,000). Virtual wards should target the top 0.5% of the local population at risk of hospitalisation	All people living in the area covered by Pembrokeshire County Council (population 118,000)
Caseload	Around 400 per year	168 patients during pilot phase (2011/12)	Around 25 patients per year in Greenwich and 20 in Bexley	0.5% of each practice's weighted population – on average, 39 beds per virtual ward, ranging between 11 and 70	Between 50 and 80 depending on team size and geographic area
Funders	50% NHS funding, 50% Macmillan Cancer Support	Fully funded by local clinical commissioning group with some additional funding from local authority and third sector organisations	No specific funding; time needed for staff to make home visits is written into job descriptions	Funded by NHS England through use of incentive schemes targeted to improve quality of care in primary care	Joint funding by health and social care system in Wales

Table 2: (continued)

	Midhurst Macmillan Palliative Care Service	Sandwell Esteem Team	Oxleas Advanced Dementia Service	South Devon and Torbay virtual wards	Pembrokeshire community resource teams
Model type (organisational integration)					
Breadth of integration	Horizontal integration in a multidisciplinary team with elements of vertical integration through consultant input, and some connections to acute and tertiary services; strong links to primary care services (GPs, district nurses) but no full integration	Horizontal integration (multidisciplinary team); some vertical integration with a view to improving primary and secondary care co-ordination	Horizontal integration (multidisciplinary team) with view to expanding vertical integration by improving co-operation with hospitals and nursing homes	Horizontal (multidisciplinary teams); linkage to secondary and ambulance services, but no full integration	Near-complete horizontal integration within teams, with some pooled funding and resource use; elements of vertical integration with acute care
Degree of integration	Integrated provider model on community health level; co-ordinated model with other care providers and social care	Full integration within community and primary care; co-operation but not integration with social care	Greenwich: full integration of community and social work team, pooled budgets and management structures; Bexley: social worker is part of multidisciplinary team, but no integration of health and social care	Fully integrated provider model for team; co-ordinated model with other care providers	Integrated provider model on community health and social care level, including third sector organisations; low but increasing vertical integration with acute sector and GPs
Information management (functional integration)					
Use of shared electronic medical records	Only within the team. Reliance on face-to-face and telephone conversation to exchange information with primary care team as well as use of notebook at patient's home	Limited - integrated community health information, with data-sharing agreements with other providers and services (eg, probation). No integration with social services and GPs	Limited for both Greenwich and Bexley, even within teams, as mental health and community staff use different systems. Some staff can access social care information technology (IT) system and vice versa. Use of mobile phones, face-to-face and email communication	Limited - integrated community health and social care information system, with some provision for out-of-hours services; GP systems separate but accessible by health and social care co-ordinators in GP practices	A system is in place giving social and health care workers access to each other's records, but it is complex and slow and underused. Staff prefer and rely on face-to-face, telephone and email communication
Use of risk stratification	Informally through clinical assessment. No use of a tool	No	No	Yes - virtual wards use predictive risk modelling tool	No, although there are plans to introduce a tool
Providers (professional integration)					
Direct	Consultants, clinical nurse specialists, health care assistants, physiotherapists, occupational therapists	Care co-ordinators, counsellors, GPs, social workers, maternal mental health workers	Consultants, social workers, district nurses, clinical nurse specialists, care co-ordinators, community matrons	Care co-ordinators, community nurses, occupational therapists, physiotherapists, social workers, GPs, voluntary sector, district nurses, clinical nurse specialists	Social workers, district nurses, chronic conditions specialist nurses, physiotherapists, occupational therapists, resource managers, third sector organisations
Indirect	District nurses, GPs, home care, hospital-based consultants, hospices	Third sector organisations, local council, acute trusts, specialist care	Third sector organisations, home care, hospital-based consultants	Home care	GPs, acute sector hospitals, home care; plans to expand integration with GPs and acute sector

Table 2: (continued)

	Midhurst Macmillan Palliative Care Service	Sandwell Esteem Team	Oxleas Advanced Dementia Service	South Devon and Torbay virtual wards	Pembrokeshire community resource teams
Approach to care (service integration)					
Single point of referral	Yes – referrals from multiple sources	Yes – one central hub, but the team also accepts direct referrals from probation and maternal health services	Yes – referrals from multiple sources	Yes – cases identified through risk stratification tool, in some instances by team members	Yes – social care has one central hub, but team members refer patients at the meetings
Eligibility criteria	Yes – people at end of life with complex needs	No – although criteria are now being developed	Yes – advanced dementia scale	Yes – as identified by risk assessment tool	No – although criteria are now being developed
Single assessment	Yes	Yes	Yes	Yes	Yes
Care planning	Yes	Yes, but strong ad-hoc element	Yes, but strong ad-hoc element	Yes	Yes, but informal; in process of being formalised
Care co-ordinator or case manager	Case manager	Care co-ordinator	Care co-ordinator	Case manager	Care co-ordinator
Multidisciplinary team	Yes	Yes	Yes	Yes	Yes
Use of financial incentives	No	Yes	No	Yes	Yes
Use of non-financial incentives	No	Yes – GP engagement through peer pressure and mental health training	No	Yes – GP engagement through peer pressure	Yes – GP engagement through peer pressure
Engaged users (personal integration)					
Self-management support	Yes – but limited due to patient's status (at end of life)	Yes – very strong element delivered throughout the programme	Yes – but limited due to patient's advanced condition	Yes – on low level through voluntary organisations and care co-ordinators	Yes – through voluntary organisations
Focus on supporting informal carers	Limited – carer assessment and bereavement support	Yes	Yes	Yes – by care co-ordinators and voluntary sector	Yes – through voluntary sector support
Other components					
Voluntary sector broker	Yes	Yes	No	Yes	Yes
Peer support	No	Yes	No	No	No
Elements of co-production	Yes – patient and carer feedback lead to organisational service adjustments	Yes – active involvement of patients and former patients in design of services	No	No	No
Carer assessment and support	Yes – part of patient assessment	Yes – identification and registration of carers, referral to support services	Yes – identify carers' needs on case-by-case basis and offer/organise support	Yes – carer registration and support from voluntary sector	Yes – assessment of carers' needs is a routine part of patient assessment in Wales

Table 2: (continued)

	Midhurst Macmillan Palliative Care Service	Sandwell Esteem Team	Oxleas Advanced Dementia Service	South Devon and Torbay virtual wards	Pembrokeshire community resource teams
Results					
User and professional experiences	Patients and carers feel supported and less anxious; staff have high satisfaction levels	Patients and carers feel supported and empowered; staff have high satisfaction levels	Patients and carers feel supported and less anxious; staff have high satisfaction levels	Increased staff motivation and positive evaluations from GPs	Team mostly positive about the approach, but some dissatisfaction about workload and lack of funding
Care outcomes	High levels (>90%) of enabling patients to die in place of choosing; lower A&E admissions compared with hospice care	25 patients on SMI register improved and discharged from register; statistically significant improvement on clinical and wellbeing scales (with no control for regression to the mean)	Improved quality of life scores for patients and carers	Improved care co-ordination resulting in shorter waits and improved independence (not yet formally evaluated)	Not yet known, although anecdotal evidence suggests improved patient satisfaction
Utilisation of services	Reduced A&E admissions and number of deaths in institutional settings	Some data suggests that secondary care use is declining, although methodologically difficult to attribute to Esteem Team and Sandwell hub	Patient audit of 2009 suggests fewer than expected A&E admissions and residential care admissions for patients involved in the service	Fewer residential home placements. Initial reduction in A&E admissions and length of stay has not been sustained over time	2012/13 results: reduction in admission rates for chronic obstructive pulmonary disease (COPD) patients. Below-average length of stay for diabetes, COPD and coronary heart disease (CHD) patients compared with local health board averages. Almost has the continually lowest delayed hospital discharge percentages of all areas covered by the health board
Cost-effectiveness	Lower cost of care for patients in last 12 months of life compared with hospice care, as early referral into the service can prevent A&E admissions	Improved system performance by efficient use of allocated budget	Reduced costs to NHS and social care commissioners	Improved quality of care at no extra cost	Evaluation of cost still ongoing; indications of reduced care costs through improved care co-ordination

Approaches to care co-ordination: a comparative analysis

Aims and objectives

As Table 2 illustrates, there are a number of similarities and differences in the approaches adopted by each programme to support people with complex health and social care needs in their communities. In terms of the key aims and objectives, all five case study programmes share a common goal: making a positive difference to the quality of life of service users through improving people's mental and physical wellbeing. In all cases, this objective has been linked to measurable care outcomes such as: enabling people to die in the place of their own choosing (Midhurst); improving mood (Sandwell); relieving carer stress (Midhurst and Oxleas); and enabling greater functional independence (south Devon and Pembrokeshire). The primary focus, however, has been to examine the holistic needs of service users and identify how they can be supported to manage their complex needs and have a better quality of life. This is consistent with evidence which suggests that the more successful approaches to managing patients with co-morbidities in primary and community care should focus on promoting functional independence rather than disease management (Smith *et al* 2012).

Avoiding or reducing unnecessary hospital admissions and promoting home-based care as an alternative to care provided in institutional settings was also characteristic of all the sites (except Sandwell). However, none of the programmes set a specific target to reduce or contain costs. While this was implicit to their work, it appears that care co-ordination has been taken forward primarily as a quality improvement strategy rather than one designed to contain costs. Indeed, while most of the case study programmes were able to demonstrate quality improvements, they could demonstrate only a marginal impact on costs (*see below*).

Target populations

Effective targeting of service users has often been cited as an essential feature of integrated care strategies (eg, Kodner 2009; Ross *et al* 2011). Taking a population management approach (as opposed to carve-out disease management strategies) that is designed to look holistically at the priority needs of local communities tends to produce better results for patients (eg, Ham 2010). Both of these elements were common features across the five case study programmes; services were made available to all people across a defined geographic area, but then targeted to those in most need, often using explicit inclusion criteria.

Another core feature of the five care co-ordination programmes is that each tended to be specifically targeted at local communities or neighbourhoods (no more than 30,000 people on average). This approach not only enabled case managers and/or care co-ordinators, together with multidisciplinary teams, to work with manageable caseloads, but also enabled care co-ordination teams to establish close working relationships with other care providers, members of the local community, and patients and carers.

Many staff from the five programmes stressed the importance of building community awareness of and trust in the model of care they had developed – for example, to ensure referrals and to support effective face-to-face communication (*see* ‘Information management’, p17). Across larger geographic areas, such as in south Devon and Torbay or Pembrokeshire, a number of multidisciplinary teams have been created to ensure that each programme has a locality focus.

Organisational development

Another key characteristic of the five programmes is that each underwent a developmental phase or piloting process, often with specifically allocated but time-limited funds. The developmental histories for each case study programme describe a process through which their innovations have survived, adapted and grown, despite the feeling that they were often regarded as ‘outside the system’ and lacking some legitimacy. Nonetheless, most programmes now describe their approach as ‘embedded’ – ie, it has become an accepted way of working within their local health economy – an achievement that can take at least six to seven years.

It has often been said that innovations in integrated care need to be given considerable time to ‘bed down’ as organisational models before they can achieve their objectives (Goodwin *et al* 2012) and that there is a maturity model at play in the life-cycle of their development (RAND Europe and Ernst & Young 2012). While this research appears to support these assertions, two further observations need to be made. First, most respondents from the five case study sites felt that their programmes were in a continuous state of change that needed constant nurturing. Second, the feeling of being ‘outside the system’ has remained manifest, with staff feeling vulnerable to changes in service and funding priorities. The most stable programme appears to be in South Devon and Torbay CCG, where health and social care commissioners had joined forces to actively lead and promote integrated models of care, allowing them to develop over time.

Organisational model

All five case study sites had sought to develop strategies of ‘horizontal integration’ across local communities based on the creation of multidisciplinary teams drawn from a range of health and social care agencies. The range of members within these core teams appears to demonstrate the importance of a diverse yet ‘dense’ community-based network of professionals working closely together. However, there appears to be an exception, in that local general practitioners (GPs) are not often central to the care co-ordination process and have varying degrees of engagement both within and across the case study sites.

This lack of engagement from GPs represents a curious paradox, as one of their core roles is to provide continuity of care to local people and act as the patient’s advocate through referrals to other services. This phenomenon does not appear to be limited to the United Kingdom; possible reasons for it include (after Goodwin *et al* forthcoming):

- GPs’ preference to work as independent practitioners
- a payment model that places the work of GPs outside the wider health and social care system
- the lack of time to get involved in care planning (for example), given intense workloads
- lack of sufficient remuneration for the work involved.

As a result, success in fostering relationships with GPs varied greatly across the five case study sites. GPs had the strongest involvement in south Devon and Torbay, where the virtual wards are hosted by each GP practice, placing GPs at the heart of the model; direct

financial incentives for GPs and practice staff also mean they are fully involved in the care co-ordination process. In contrast, the Oxleas model is hosted by a secondary care provider, distancing professionals from GP practices and making it more difficult for specialist nurses and community matrons to develop strong links to primary care. Positioning and remuneration, then, seem crucial when it comes to engaging GPs in care co-ordination.

While the multidisciplinary teams in each programme had moved in the direction of becoming fully integrated community-based models of care – some with separate funding and governance arrangements – the degree of ‘vertical integration’ with hospitals appears to have remained weak. At best, the case study sites had managed to create ‘linkages’ – for example, with key clinicians to share information and/or raise awareness, or to develop strategies to avoid unnecessary hospital admissions and to secure early discharge – but all sites reported this as under-developed and cited the need to develop better relationships with hospitals, especially when managing effective care transitions from hospital to home.

Funding

One of the areas where there was little commonality was in the way co-ordinated care programmes were being funded. Indeed, the funding histories across the five sites show how programme leaders have had to take an entrepreneurial approach to finding resources to support their innovations, particularly in the early stages. Two sites (south Devon and Pembrokeshire) had become ‘fully funded’ by joint health and social care commissioners, who also played an important role in leading and promoting the programmes. In Sandwell, resources have been pulled in from a range of different funding streams controlled by local clinical commissioning groups, but with additional funding drawn from a range of sources, including the local authority and third sector organisations. In Midhurst, 50 per cent of the programme costs each year have been supported by the Macmillan Cancer Support charity, with the remainder drawn from local clinical commissioning groups. In Oxleas, resources for the programme have been secured from internal funding within the trust.

Of all the challenges faced by the five care co-ordination programmes, funding was most often cited as the greatest concern. This was particularly the case in three areas – Oxleas, Midhurst and Sandwell – where their financial sustainability was reliant on multiple funding sources that were not guaranteed to be available in future years. For example, in Midhurst, there had been discussions about phasing out the charitable element to the programme’s funding. In Oxleas, future funding for staff remained unclear due to limited overall resources in the trust, and potentially differing priorities. Prospects for longer-term funding seemed more stable in south Devon and Pembrokeshire, where support from a single commissioner using pooled health and social care funds was available; but even here, the wider context of a squeeze on public sector budgets has brought doubts about future levels of investment. As a result, all programmes felt somewhat ‘at risk’ financially, although this was clearly a more pressing problem among those with multiple sources of funding.

Approach to care

A common approach across the five case study programmes was to encourage referrals from multiple sources, often including patients and family (*see* ‘Engaged communities’, p18). To overcome the potential challenges of managing such a process, and the additional costs implied, all programmes developed a single point of entry through which new referrals would be managed. All programmes then filtered cases through to their multidisciplinary teams to undertake case reviews, initiate assessments and develop care packages. The ability to generate referrals from multiple sources was seen as a key aspect of success – for example, in Sandwell and Midhurst, this meant support could be provided to people before they experienced a crisis (and so avoiding unnecessary hospital admissions, for instance).

All five programmes had an explicit focus on supporting people to live at home and used multidisciplinary and community-based teams as a means to achieve that. The teams typically utilised the skills of specialist nurses, primary care professionals, social care staff, allied health professionals and the voluntary sector, to conduct holistic assessments which take health and social care needs into account. None of the programmes had a pre-defined care package; they preferred instead to draw on all resources available locally to tailor care directly to the needs of individual service users. A care co-ordinator acts as a single point of contact and works with the patient, their carer(s) and the multidisciplinary team to develop a care plan. Once this has been agreed, the co-ordinators work with the team, the patient, the patient's family and other care providers to deliver co-ordinated and coherent care. Personal continuity of care is actively encouraged, and the care teams work hard to ensure an immediate response to care needs as they arise.

Care co-ordinators

The role of the care co-ordinator appears to have been crucial in enabling the programmes to deliver their objectives effectively. In other words, co-ordinating care around the needs of patients and carers requires a dedicated staff member to facilitate the process. However, the role of care co-ordinator is far more than simply navigating people between care providers. The care co-ordinator role is multi-faceted, and includes:

- providing personal continuity of care to the patient/carer, acting as a key point of contact for care
- being the patient's advocate in navigating across multiple services and settings
- providing care directly in the home environment (by case managers with advanced skills)
- ensuring that professionals within the multidisciplinary team are kept informed of the patient/carer's situation
- taking accountability for the provision of care and ensuring that care packages are put in place and delivered
- communicating with the wider network of providers (outside of the core multidisciplinary team) so that information about the patient/carer is shared and any actions required are followed up.

These key functions of the care co-ordinator were consistent across the five programmes despite differences in the nature of the patient group being served and whether they were located in rural or urban settings, affluent or deprived communities, or dealing with smaller or larger caseloads. However, the type of person undertaking the care co-ordination function varied greatly. Most care co-ordinators had been community or specialist nurses, yet the role has also been taken on by non-clinical 'link workers' (in Sandwell) and health and social care co-ordinators (in Torbay). There appears to be a continuum from the non-clinical approach – primarily providing personal continuity to service users and acting as their advocate to ensure that care is co-ordinated around their needs – to the clinical approach, in which a case manager would also be able to provide clinical care directly (*see also* Goodwin *et al* forthcoming).

None of the care co-ordinators had received any specialist training for the role, but all reported having good 'people skills' and in-depth knowledge about the local community. Most had lived and worked in their community for several years, acquiring a good understanding of the local health or social care system, which helped them to support patients in negotiating between care providers. Building effective working relationships between care co-ordinators, multidisciplinary teams and wider service providers has been important in supporting better co-ordination.

Team culture

Feedback from programme participants combined with observational analysis revealed that all five of the programmes placed considerable emphasis on team-building and networking within the core multidisciplinary teams providing care. It was commonly reported that building a supportive team culture did not happen in a vacuum; it required continual nurturing over time to reinforce the shared vision and personal commitments needed to enable the programmes to succeed. Indeed, one characteristic underpinning the success of each case study programme was the personal commitment demonstrated by staff – both managers and professionals – to go that ‘extra mile’ by working beyond the boundaries of their job description in order to achieve the best results for their patients, and in supporting colleagues to do the same. We found a range of explicit strategies that promoted a strong ethos among staff to ‘do the right thing’ – for example: promoting the needs of patients before their own needs; supporting knowledge-sharing; and enabling role substitution through staff empowerment.

Developing a collaborative culture has often been put forward as a key ingredient of integrated care. What was striking in our research was the consistent emphasis placed on ‘creating energy for change’ through an ability to build social capital and promote engagement and learning between partners in care across the local community. This took considerable time and effort and sometimes meant that progress was slow as a result; yet it was also recognised as a necessary process and catalyst for change.

Information management

Approaches to information management varied widely, but the lack of access to shared electronic health records was a common issue. In all sites, it was reported that a significant amount of time and effort had, therefore, to be placed on interpersonal communication between members of the multidisciplinary team, but also with other care providers such as GPs. Strategies included face-to-face meetings, ensuring telephone or email follow-ups, and creating joint records through notes left at patients’ homes. All of these strategies were witnessed – for example, in the Midhurst programme, where responsibility for keeping everyone informed was taken forward by the clinical nurse specialists acting as the patient’s care co-ordinator. This included attending regular meetings in each GP practice to report back on patient care and to seek input and advice from all team members. In all five programmes, the regular multidisciplinary team meeting was the hub of communication and knowledge exchange, where specific cases (current and new) were discussed.

This ‘low-tech, high-touch’ approach was viewed by professionals as both a challenge to be overcome but also as an asset to be retained. All sites reported that the effectiveness of decision-making and communication could be significantly improved through access to shared health care records and better technology. The process of checking records on separate health and social care systems, for example, was seen as onerous, and keeping all partners well informed of a patient’s situation was highly time-consuming. However, it was commonly reported that there was great value to this level of face-to-face communication with colleagues as a way of building trust, fostering collaboration and having more meaningful conversations about the needs of patients with complex conditions. Hence, information technology (IT) was seen as a potential tool to improve communication, but personal interactions remained essential.

In the absence of data to support risk stratification, developing community awareness and vibrant networks of communication between partners in care and the community has enabled co-ordinated care teams to get earlier warning of people in need of care who might otherwise have fallen into crisis. Such networking, for example, was reported as being particularly important in identifying people nearing the end of life and referring them to Midhurst, and so helping to support them at home without the need for

hospitalisation. In Sandwell, strong community-based networks have enabled earlier referrals from people with mental health needs who would not otherwise have been supported. Hence, while the lack of integrated medical records was seen as a potential disadvantage, the case study programmes placed great importance on networking strategies to ensure effective communication about the needs of service users.

Engaged users

Without exception, all five programmes sought to promote engagement with service users and their informal carers or family members. Indeed, all had developed explicit strategies and tools to support self-management, with a specific emphasis on undertaking carer and family assessments on which to build a range of support packages to meet each patient's needs. For patients with complex needs, especially those nearing the end of life (Midhurst and Oxleas), building resilience among carers to cope with supporting the long-term management of patients at home has been a key strategy. All sites were aware that shifting care for patients with complex needs into the home environment would place added burdens and responsibilities on carers; focusing on the needs of carers directly has therefore proven to be effective in helping to alleviate stress and anxiety, resulting in positive views about the programmes among patients and their carers. This approach typically included bereavement support and counselling after death. However, there was less evidence within the sites of shared decision-making with patients and carers (for example, during care planning).

Engaged communities

Community engagement, incorporating the voluntary sector, has also proved central to what the five case study programmes have been able to achieve. In Midhurst, Pembrokeshire and south Devon (but not yet in Torbay), the voluntary sector has been brought into the core multidisciplinary team. In south Devon and Pembrokeshire, volunteer 'brokers' attend team meetings, taking part in the discussion of cases and development of care plans; while in Midhurst, the volunteer co-ordinator plays the same role and uses this information to identify and deploy volunteers matched to individual patients. In Sandwell, community groups are engaged as partners in care and many members of the community (including previous service users) have taken on specific support roles. In addition to utilising volunteers within the care programmes, all sites placed a premium on building community awareness and trust with local populations as a strategy to ensure that people knew their services were available and would therefore be more likely to recommend and signpost friends and family to the programmes.

Evaluation of impact

The five care co-ordination programmes were selected in an open competition to be part of the case study research (*see* Appendix A). A key criterion for selection was that each had to have been able to demonstrate evidence of a positive impact on one or more (but preferably all) of the following: patient experiences, care outcomes and cost-effectiveness. However, the results of the application process revealed a chronic lack of attention to demonstrating and measuring outcomes. Few programmes used patient feedback proactively to reflect on care services provided; information on care outcomes was not routinely collected; and changes to the utilisation and costs of services have been rudimentary (Goodwin 2012).

The business of monitoring and measuring outcomes on care co-ordination therefore does not appear to be strongly valued (culturally or managerially) in the National Health Service (NHS) as a way of judging performance. It should be stressed that this problem is not just confined to the NHS and the United Kingdom; international studies have also shown this to be a problem, especially in publicly funded health systems (Goodwin *et al* forthcoming). This lack of evidence for care co-ordination is a key reason why there are relatively few

demonstrable examples of success (Ham and Walsh 2013) and may partly explain why such innovations often fail to progress past the pilot phase into mainstream thinking and practice (Goodwin *et al* 2012).

However, all five case study programmes were in the process of developing robust methods to demonstrate impact, though none had actively developed such strategies from the outset. As Table 2 (on p12) shows, all the sites were able to provide some evidence to support the beneficial impact of their programmes. However, the quality and robustness of this evidence can best be described as weak, with only one programme (Midhurst) having conducted an independent evaluation (Thiel *et al* 2013a).

When reviewing impact data from the five sites, one of the key concerns was the methodological weaknesses that affected whether improvements could be directly ascribed to each programme's work. For example, statistically significant improvements in the mental health of patients in Sandwell may have been the result of 'regression to the mean' rather than the direct efforts of the Esteem Team to improve clinical outcomes. Similarly, reduction in hospital admissions for patients with chronic obstructive pulmonary disease (COPD) in Pembrokeshire over one year may have been random, so attributing outcomes directly to the work of the community resource teams is problematic.

A common objective across all the care co-ordination programmes has been to support people to live at home to avoid unnecessary hospitalisation. Yet it is difficult to ascertain how many hospital admissions may have been avoided. Apart from Midhurst, no site has carried out a study comparing outcomes for their patient population with a group that did not receive the intervention.

Supporting an evaluation study with control groups was seen as too expensive or too time-consuming for most programmes to contemplate. In terms of patient and carer experiences, most case study sites had undertaken some kind of investigation in the form of questionnaires, focus groups or narrative case studies. However, no quantitative evidence was available, either because the sites had not carried out large-scale surveys or because their approach was at a relatively early stage.

The lack of robust evidence on cost-effectiveness and the problems related to attribution are common problems in this field. Recent evaluations of 16 integrated care pilots and 30 integrated community care projects in the United Kingdom have identified similar methodological difficulties (Bardsley *et al* 2013; RAND Europe and Ernst & Young 2012). Nonetheless, despite these methodological constraints, the overall evidence across the five case study programmes suggests that it is legitimate to claim that care co-ordination can improve the quality and experience of care for patients with complex conditions without adding to overall system costs. However, the likelihood of care co-ordination being able to generate significant cost savings is low when delivered at the scale on which the five case study programmes were operating. Given that none of them had an explicit objective to generate financial savings, the strategy they have followed can best be described as one of quality improvement rather than cost reduction. The inability to demonstrate cost-effectiveness, however, is a weakness that may have negative consequences given the tentative nature of ongoing funding.

Building care co-ordination programmes: key challenges and facilitators

Key challenges

It takes time to build an effective programme of care co-ordination, and the history of the five case study sites reveals that this path has not been easy. A number of common challenges emerged, and fundamental to these is the fact that care co-ordination programmes have been developed within systems of care that do not treat such innovation as ‘core business’. Silo-based thinking and existing medical paradigms have perhaps been the greatest challenges at the clinical and service level. In Midhurst and Oxleas, for example, both programmes needed to convince other care professionals – particularly specialists – that it was possible to provide palliative care in people’s own homes, without the need for hospital beds.

There was often strong reluctance to refer patients to programmes that were seen as outside existing professional norms and values, which is why all five sites emphasised the need to ‘win hearts and minds’ to ensure that their service was accepted and used. All programmes reported making huge efforts to ensure effective communication between partners in care, with most heavily reliant on face-to-face communication, email exchanges (where permissible) and telephone conversations. The lack of integrated information technology (IT) systems to better support information exchange has proved to be a major challenge for all sites due to the incompatibility of existing health and social care IT systems; as a result, the time burden related to communication has been heavy.

Funding has been, and remains, a significant concern. As discussed in the comparative analysis above, a key challenge to the future of the programmes has been the ability to find longer-term and more secure resources. This has been a particular problem where funding has had to be drawn from multiple sources on a time-limited basis, increasing the complexity of relationships across different funders as well as adding to the feeling of being ‘at risk’. In contrast, having a single source of funding, as in the commissioner-led schemes in south Devon and Pembrokeshire, has enabled a greater degree of stability. Yet even where funding has been secured for the long term, it is often seen as insufficient to increase staffing levels, fund enhancements, and meet ever-increasing demands from patients.

All sites agreed that the lack of general practitioner (GP) engagement had contributed to slower than anticipated progress, in terms of the ability both to provide effective care co-ordination and to ensure referrals into their programmes. A variety of strategies to improve GP engagement have been used – for example, financial incentives, information sessions and attending regular GP meetings. However, none of the programmes had yet achieved the desired level of engagement with GPs other than in south Devon, where virtual wards were hosted by GP practices.

A final key challenge identified by the case study programmes was the provision of effective care co-ordination for people living in remote and rural locations. Providing home-based care that can respond quickly to people's needs appears to be a hallmark of the strategies developed to support people with complex needs; yet rurality and its associated challenges (covering long distances, which reduces capacity and increases costs) has presented particular problems for the case study programmes. In both south Devon and Pembrokeshire, interviewees remarked how it was far more difficult in remote locations to identify complex cases earlier and so help prevent deterioration through packages of care support.

Key facilitators

While staff involved in the programmes often described having to think laterally to work around existing regulatory and organisational rules in order to establish their programmes, there was a sense that each had benefited from a supportive political narrative that actively encouraged the development of person-centred care co-ordination. Indeed, depending on the nature of the patient group, programme leaders used the leverage contained in best practice guidance to justify continued funding and support. For example, the Sandwell Esteem Team was helped by policies seeking to increase access to psychological therapies (IAPT), while in Oxleas, the programme was supported by a national strategy to improve diagnosis and treatment of dementia patients in primary and secondary care. National efforts to improve end-of-life care and to enable people to die in a place of their choosing had also given added credibility to the Midhurst programme.

Consistent with other experiences where integrated care has been effectively implemented (eg, Ham and Walsh 2013), local leadership and commitment have been essential ingredients. In each of the case study programmes, interviewees identified between one and three key leaders responsible for the successful development and operation of their programmes. These people's dedication to improving services for patients and their ability to not be limited by the status quo was seen as essential for initiating the programmes and challenging perceived wisdom about how care can best be provided. Long-term association with the programmes was also seen as essential in providing the 'leadership continuity' required to drive through innovation and change.

Closely related to the dedication of key staff was the development of a clear joint vision for how better patient care could be achieved. All interviewees agreed that success hinged on ensuring that this vision was shared by all stakeholders (staff, external organisations, patients and carers, voluntary sector organisations, etc); indeed, many interviewees pointed to the fact that present-day problems in care delivery could be traced to a past lack of engagement with, or by, a particular group of stakeholders.

A key feature accounting for the success achieved by all five programmes has been their ability to react flexibly to the changing needs of patients. There are no pre-defined care packages; care plans are developed together with patients and carers and are tailored to meet their needs. The ability to react in real time to sudden changes in a patient's condition was seen as crucial for patients with complex needs, whose health status can deteriorate quickly and for whom the progress of their illness can be unpredictable. The programmes used a range of strategies that promoted a strong ethos among staff to 'do the right thing' – for example: promoting the needs of patients before themselves; supporting knowledge-sharing; and enabling role substitution and subsidiarity through staff empowerment. Allowing professionals to 'use common sense' (specifically for non-clinical care) meant that many had undertaken tasks that may not be strictly related to their professional roles, but have resulted in faster and appropriate intervention for the patient.

Finally, a critical component of care co-ordination for people with complex needs is the unpaid support provided to patients by informal carers, family and volunteers from the local community. The ability to support people to live at home, or to ensure that an effective 'early warning' system is in place before they fall into crisis, requires 24/7 support that cannot be provided by the limited resources available to health and social care teams. This seems especially important for highly vulnerable patients nearing the end of life. Experiences from the Midhurst Macmillan Service and Oxleas Advanced Dementia Service show the central importance of family members and volunteers in fulfilling such roles. Both programmes have invested in building the resilience of carers to support patients at home and in engaging with the wider community to provide a range of essential 'low-level' support services that help people remain independent and at home for longer.

Conclusions

The purpose of this report has been to uncover the key lessons and markers for success in how care co-ordination might be effectively transferred between different contexts and settings. Findings from our research into five UK-based case study programmes suggest that there are a number of transferable lessons in how to approach care co-ordination for people with complex needs at a clinical and service level; yet the success of such approaches can be significantly influenced by the contexts within which programmes operate. Hence, a multi-level analysis has been provided here to describe the key success factors in building and delivering an effective programme of care co-ordination.

Personal level

- Care co-ordination for people with complex needs requires a holistic focus on the needs of both patients and carers.
- Explicit strategies are required that promote engagement with service users, particularly to promote self-management through a range of support packages that meet their needs.
- Approaches appear to be more effective where they focus on promoting functional independence and wellbeing, enabling people to cope and live well with their conditions rather than a purely clinical focus on managing or treating medical symptoms.
- Building resilience among carers is important in the promotion of home-based care and can be effective in alleviating stress and anxiety.
- Relational continuity of care with named care co-ordinators is highly valued and, by having just one person to call, can enable real-time issues to be dealt with more effectively.

Clinical and service levels

- Supporting referrals from multiple sources, including directly from those living in the community, can enable professionals to put services in place before crises occur.
- Having a single point of entry helps co-ordinate these referrals more effectively and provides a single contact point for patients and carers.
- The role of the care co-ordinator appears to be crucial in supporting the management of referrals and enabling programmes to deliver their objectives effectively.
- The care co-ordinator role is flexible and multi-faceted, and can include:
 - managing referrals
 - providing personal continuity of care to the patient/carer and taking accountability to ensure that care packages are put in place and delivered
 - being the patient's advocate in ensuring that professionals within the multidisciplinary team are kept informed of the patient/carer's situation
 - providing care directly in the home environment

- communicating with the wider network of providers (outside of the core multidisciplinary team) so that information about the patient/carer is shared and that any actions required are followed up
- helping patients to navigate across multiple services and settings.
- Care co-ordinators need to be imbued with responsibility and power to exert influence within the local health system. Without this they can become isolated, demoralised and ineffective.
- A comprehensive and holistic health and social care assessment, including that of carers' needs, is necessary to enable the development of a personalised care plan.
- Care plans need to be tailored directly to the specific needs of individual service users. No defined care packages are set in advance and service provision is geared to providing a flexible response to patients as their care needs change over time.
- Multidisciplinary teams, working to a common set of objectives and priorities that bring together a range of specialist and generalist skills, effectively combine to support people to live well at home.
- Team-building is important, focusing on reinforcing a shared vision and personal commitment from staff to achieve the best outcomes for patients.
- Flexibility within the care team is essential, supported by approaches that enable role substitution through staff empowerment.

Community level

- The role of volunteers and third sector organisations in supporting the needs of patients and carers gives important added value to care co-ordination programmes – for example, through the role of a volunteer 'broker'.
- The role of the community should be seen as integral to the care-giving process and, where appropriate, this role should be formalised into supporting the work of the multidisciplinary teams.
- Building community awareness and trust with local populations and other care providers can give greater legitimacy to new approaches to care. This can increase the likelihood of referrals into a programme, enabling people in need of care to be identified and cared for earlier, thereby potentially avoiding a crisis.

Functional level (information management and communication)

- A significant amount of effort is required to ensure effective communication between members of the multidisciplinary team, and also with other care providers involved in patient care.
- Access to shared electronic health records would add significant value to the ability to share information, but it is not an essential attribute of well-performing approaches to care co-ordination.
- A 'high-touch, low-tech' approach has value in promoting face-to-face communication, fostering collaboration and enabling meaningful conversations about the needs of patients with complex conditions.

Organisational level

- A population management approach is required to holistically examine the needs and priorities of a defined geographic population.
- Effective targeting of service users is required to prioritise care provision, supported where possible by the intelligent use of data to enable risk prediction.

- Programmes of care co-ordination need to be localised so that they concentrate on specific communities and neighbourhoods. Larger populations will require a range of locality-based programmes operating together.
- Local leadership and long-term commitment – from commissioners and providers – are important for the successful development of care co-ordination programmes in practice.
- Early on in programme development, partners in care should develop a shared vision and shared understanding about how the care process should be changed to better support patients. Challenging silo-based thinking and overcoming structural and funding constraints first requires a shared agreement on the need to change and how this might best be achieved.

System level

- Programmes of care co-ordination in the United Kingdom have developed within a fragmented overall system of care that has limited their potential to become embedded and accepted as new ways of working.
- Having a single source of funding from an integrated health and social care commissioner can support longer-term strategies and provide a greater degree of stability.
- A political narrative that supports innovation in person-centred care co-ordination has provided much-needed credibility and support.

Key observations

Programmes of care co-ordination, like those investigated in this research, take many years to grow from development projects into more mature models of care. However, the process of programme development does not appear to reach an ‘end point’; and new approaches that lie at the margins of what might be regarded as ‘core business’ appear to remain somewhat ‘at risk’, since their future is not guaranteed. Consequently, success in care co-ordination appears to be the result of a long-term process, facilitated by key local leaders, during which the capability and legitimacy of new ways of working is built up over time (at least six to seven years in the context of this study).

A common observation by the key leaders in each programme was that ‘there was no substitute for going through the process of development’ since so much of their success was built on forging and nurturing alliances. Hence, a key lesson is that different approaches to care co-ordination have highly context-specific histories and cannot be transported ‘en bloc’ from one location to another. Achieving effective programmes of care co-ordination requires a bottom-up process to develop the building blocks for effective partnership working, rather than introducing new top-down models of care, no matter how well they may have worked in other settings. Understanding the local context, then, is the key to transferring lessons from other programmes of care co-ordination.

Another key lesson is related to the degree of realism that is required when it comes to estimating the impact that care co-ordination might have on costs. It has often been assumed that care co-ordination for the most ‘at-risk’ groups, particularly in the form of intensive case management, can reduce hospitalisations and therefore save money (Ross *et al* 2011). However, while all of the programmes of care co-ordination that we examined were able to demonstrate improvements in care experiences and outcomes, impact on reducing costs and improving cost-effectiveness was limited. This suggests that managers and policy-makers need to be realistic about the potential financial impact of care co-ordination, and view the approach primarily as a quality improvement strategy rather than one specifically aimed at cost reduction.

The experience of the five UK-based care co-ordination programmes tells us that their approach largely remains ‘outside’ of the way care systems have traditionally operated. This means they have found it difficult to progress certain innovations and/or to do so relatively quickly. Of concern to all programmes was the apparent disengagement of general practitioners (GPs), which sometimes made effective information exchange difficult and prevented them from bringing the GPs’ general knowledge of the patient/family into discussions about their care. Similarly, links with secondary providers have remained under-developed – for example, in securing faster access to specialist knowledge in the care process and ensuring better quality transitions from hospital to home. The latter point is important given growing evidence from the United States that a strong focus on care transitions can help reduce readmission rates (eg, Jackson *et al* 2013).

Hence, all five case study programmes recognised that progress would have been easier if they were operating in a more integrated delivery system – for example, where purchasing, planning, organisation and governance practices were more closely aligned. In the United States, the fact that care co-ordination models have tended to flourish within different ‘integrated delivery systems’ of care tells us that a supportive operating environment is important. Of the five UK-based programmes examined in this research, there was some evidence to suggest that there were advantages to having more ‘fully integrated’ provider teams working closely with a single health and social care commissioner.

Nonetheless, even where care programmes were operating within a more integrated delivery system, there were still significant challenges – for example, in making the case for continued or increased funding to build capacity and invest in new ways of working. To this end, the apparent lack of strategic attention to demonstrating impact in terms of care outcomes and/or costs remains a fundamental deficiency. Far greater attention is required to measure and reflect on performance, not only to justify levels of investment but also to reflect objectively on the quality of care being provided.

The characteristics of the five UK-based programmes of care co-ordination reinforce much of what was known about the components of successful approaches to integrated care (*see* Table 1, p 2). However, several key elements detailed in previous literature were not present in most of the sites, suggesting that these components are perhaps not so critical for successful care co-ordination. For example, single or shared clinical records were not evident in the programmes (except in Torbay, where social and community care teams can share data) and there was no evidence of continuous/remote patient monitoring; there were no formal discharge/transfer agreements (except in Pembrokeshire, where joint discharge and community teams based in the local hospital work with community resource teams); and there were no inter-professional networks to promote education and learning. Specific decision support tools, care guidelines and protocols were also not commonly used (except in Midhurst) and there was an absence of defined care packages. It might be concluded that dealing with patients with complex needs means that it is inappropriate to develop a protocol-driven approach, since care pathways are unpredictable (ie, there is no such thing as ‘usual care’) and greater flexibility in service response is required. However, it might also be the case that such approaches are less developed in the UK context. Either way, achieving success in care co-ordination does not appear to have been hindered in their absence.

One of the more problematic questions for the future is whether and how small-scale programmes of care co-ordination can be scaled up. This is a particular concern given the limited impact demonstrated by the case study programmes on cost-effectiveness. Yet this research suggests limits to the scale of operations at the service level, because the process appears to flourish at the neighbourhood level, where the benefits of close engagement with local communities sit alongside the need to have good working relationships within

multidisciplinary care teams dealing with manageable caseloads. However, lessons from south Devon and Torbay suggest that it is possible to scale up through building a number of locality-based approaches to care under the direction of an umbrella organisation. Yet in each case, the process of relationship-building takes time and, as in Pembrokeshire, is likely to lead to variable approaches to care in local contexts that may or may not be as successful.

As a final observation, it is clear that building effective programmes of care co-ordination requires ‘simultaneous innovation’ at the organisational/management level in addition to new approaches to care at the clinical/service level. As other studies have shown, without the full alignment of political, regulatory, organisational and professional support to the goals of integrated care, too much reliance is placed on local leaders to make change happen (Goodwin *et al* forthcoming). Ultimately, the long-term future of care co-ordination programmes requires care systems to directly value their contribution in meeting the growing demands of people with long-term and complex chronic conditions.

Appendix A: Methodology

Site selection

The five case studies were selected following a competitive call by The King's Fund across the United Kingdom for care co-ordination programmes to be included in the research. An expert multidisciplinary panel drawn from both the United States and the United Kingdom supported The King's Fund in selecting the sites for inclusion in a review process using objective criteria.

Literature review

The research team carried out a non-systematic literature review to establish the *a priori* criteria for effective care co-ordination with the aim of comparing these criteria with findings from each case study site.

Fieldwork

In-depth case study fieldwork was carried out between October 2012 and May 2013. The research team, consisting of two researchers and a senior research fellow, visited all five case study sites to interview key internal and external stakeholders from multiple professional backgrounds. Semi-structured face-to-face interviews were undertaken, with follow-up by telephone where appropriate. Interviews were recorded, transcribed and analysed using a common coding framework and NVivo software. At each site, the research team also observed at least one team meeting using a template to record team behaviour, topics discussed and actions recorded. Furthermore, the research team carried out content analysis of documents from each site and undertook secondary data analysis to verify each programme's reported outcomes. The table below provides details of the process.

Case study	Date of field visit	Additional interviews (telephone)	Number of interviews	Location
Midhurst Macmillan	8 Oct 2012–10 Nov 2012	19 Nov 2012–14 Feb 2013	20	Pulborough, Midhurst
Oxleas	2 Nov 2012; 19 Nov 2012; 26–29 Nov 2012		14	Bexleyheath, Greenwich
Sandwell Esteem Team	14–17 Jan 2013		12	Sandwell, West Bromwich
South Devon and Torbay	11–13 Mar 2013	23 Apr 2013	15	Newton Abbot, Torbay, Ashburton
Pembrokeshire	13–17 May 2013		18	Haverfordwest, Milford Haven, Pembroke Dock

Development days

In addition to the fieldwork, six development days were held, bringing together representatives from each case study programme to discuss common issues and explore how to resolve these. One development day was held at each case study site, with an additional day held at The King's Fund in London.

For more information on the methods used in this research, visit the project website at: www.kingsfund.org.uk/projects/co-ordinated-care-people-complex-chronic-conditions

References

- Agency for Healthcare Research and Quality (2012). *2012 Annual Progress Report to Congress National Strategy for Quality Improvement in Health Care* [online]. Available at: www.ahrq.gov/workingforquality/nqs/nqs2012annlrpt.htm (accessed on 4 October 2013).
- Bardsley M, Steventon A, Smith J, Dixon J (2013). *Evaluating Integrated Care and Community-Based Care: How do we know what works?* London: The Nuffield Trust.
- Bodenheimer T (2008). 'Coordinating care – a perilous journey through the health care system'. *The New England Journal of Medicine*, vol 358, no 10, pp 1064–71.
- Coleman K, Austin B, Brach C, Wagner E (2009). 'Evidence on the Chronic Care Model in the new millennium'. *Health Affairs (Millwood)*, vol 28, no 1, pp 75–85.
- Curry N, Ham C (2010). *Clinical and Service Integration: The route to improved outcomes*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/clinical-and-service-integration (accessed on 30 September 2013).
- Devers K, Berenson R (2009). *Can Accountable Care Organizations Improve the Value of Health Care by Solving the Cost and Quality Quandries?* Timely Analysis of Recent Health Policy Issues 13. Washington DC: Urban Institute.
- Epping-Jordan J, Pruitt SD, Bengoa R, Wagner EH (2004). 'Improving the quality of health care for chronic conditions'. *Quality and Safety in Health Care*, vol 13, no 4, pp 299–305.
- Goodwin N (2012). 'It's time to demonstrate the value of care co-ordination'. Blog, 11 July. The King's Fund website. Available at: www.kingsfund.org.uk/blog/2012/07/its-time-demonstrate-value-care-co-ordination (accessed on 26 September 2013).
- Goodwin N (2011). 'NHS reforms: the five laws of integrated care'. Blog, 21 July. The King's Fund website. Available at: www.kingsfund.org.uk/blog/integrated_care_laws.html (accessed on 26 September 2013).
- Goodwin N, Curry N, Naylor C, Ross S, Duldig W (2010). *Managing People with Long-Term Conditions*. London: The King's Fund. Available at: www.kingsfund.org.uk/current_projects/gp_inquiry/dimensions_of_care/the_management_of_1.html (accessed on 26 September 2013).
- Goodwin N, Dixon A, Anderson G, Wodchis W (forthcoming). *Providing Integrated Care for Older People with Complex Needs: Key insights and lessons from seven cross-national case studies*. London: The King's Fund.
- Goodwin N, Smith JA, Davies A, Perry C, Rosen R, Dixon A, Dixon J, Ham C (2012). *Integrated Care for Patients and Populations: Improving outcomes by working together. A report to the Department of Health and NHS Future Forum*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/integrated-care-patients-and-populations-improving-outcomes-working-together (accessed on 30 September 2013).

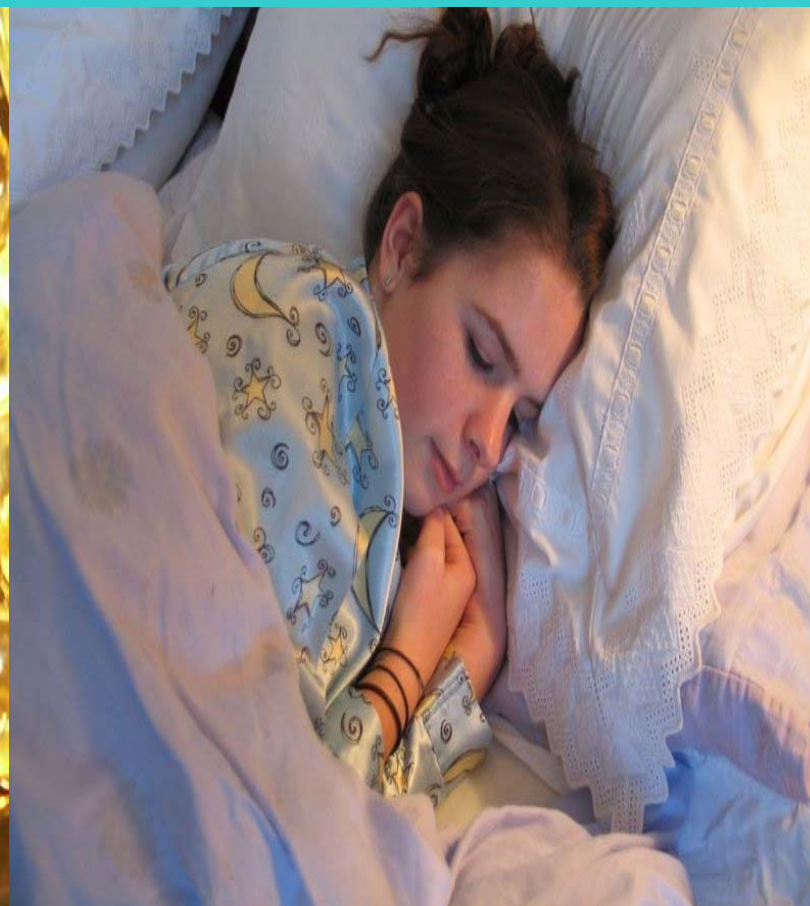
- Ham C (2010). 'The ten characteristics of the high-performing chronic care system'. *Health Economics, Policy and Law*, vol 5, pt 1, pp 71–90.
- Ham C, Heenan D, Longley M, Steel DR (2013). *Integrated Care in Northern Ireland, Scotland and Wales: Lessons for England*. London: The King's Fund.
- Ham C, Walsh N (2013). *Making Integrated Care Happen at Scale and Pace: Lessons from experience*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/making-integrated-care-happen-scale-and-pace (accessed on 26 September 2013).
- Hofmarcher M, Oxley H, Rusticelli E (2007). *Improved Health System Performance through Better Care Coordination*. OECD Health Working Paper No. 30. Paris: OECD. Available at: www.oecd.org/health/health-systems/39791610.pdf (accessed on 25 June 2013).
- Institute for Healthcare Improvements (2013). 'The IHI Triple Aim'. IHI website. Available at: www.ihl.org/offerings/Initiatives/TripleAim/Pages/default.aspx (accessed on 11 October 2013).
- Jackson C, Trygstad T, DeWalt D, DuBard A (2013). 'Transitional care cut hospital readmissions for North Carolina Medicaid patients with complex chronic conditions'. *Health Affairs*, vol 32, no 8, pp 1407–15.
- The King's Fund (2013). *Co-ordinated Care for People with Complex Chronic Conditions* [online]. Available at: www.kingsfund.org.uk/projects/co-ordinated-care-people-complex-chronic-conditions (accessed on 27 August 2013).
- Kodner D (2009). 'All together now: a conceptual exploration of integrated care'. *Healthcare Quarterly*, vol 13, special edition, pp 6–15.
- McDonald K, Sundaram V, Bravata D, Lewis R, Lin N, Kraft S, McKinnon M, Paguntalan H, Owens D (2007). *Closing the Quality Gap: A critical analysis of quality improvement strategies (Vol. 7: Care Coordination)*. Technical Review 9. AHRQ Publication No. 04(07)-0051-7. Rockville, MD: Agency for Healthcare Research and Quality.
- National Coalition on Care Coordination (2011). *Implementing Care Coordination in the Patient Protection and Affordable Care Act* [online]. Policy Brief. Available at: www.nyam.org/social-work-leadership-institute/docs/publications/N3C-Implementing-Care-Coordination.pdf (accessed on 15 July 2013).
- Øvretveit J (2011). *Does Clinical Co-ordination Improve Quality and Save Money?* London: The Health Foundation. Available at: www.health.org.uk/publications/does-improving-quality-save-money/ (accessed on 28 June 2013).
- Powell Davies G, Harris M, Perkins D, Roland M, Williams A, Larsen K, McDonald J (2006). *Coordination of Care within Primary Health Care and with Other Sectors: A systematic review*. Research Centre for Primary Health Care and Equity, School of Public Health and Community Medicine, University of New South Wales, in association with the University of Manchester (United Kingdom). Available at: www.health.vic.gov.au/pcps/downloads/careplanning/system_review_noapp.pdf (accessed on 26 September 2013).
- RAND Europe, Ernst & Young (2012). *National Evaluation of the Department of Health's Integrated Care Pilots*. London: Department of Health. Available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/215103/dh_133127.pdf (accessed on 30 September 2013).

- Roland M, Lewis R, Steventon A, Abel G, Adams J, Bardsley M, Brereton L, Chitnis X, Conklin A, Staetsky L, Tunkel S, Ling T (2012). 'Case management for at-risk elderly patients in the English integrated care pilots: observational study of staff and patient experience and secondary care utilisation'. *International Journal of Integrated Care*, vol 12, July–September.
- Ross S, Curry N, Goodwin N (2011). *Case Management: What it is and how it can best be implemented*. London: The King's Fund. Available at: www.kingsfund.org.uk/sites/files/kf/Case-Management-paper-The-Kings-Fund-Paper-November-2011_0.pdf (accessed on 26 September 2013).
- Smith S, Soubhi H, Fortin M, Hudon C, O'Dowd T (2012). 'Managing patients with multimorbidity: systematic review of interventions in primary care and community settings'. *BMJ*, vol 345, e5205.
- Sonola L, Thiel V, Goodwin N, Kodner D (2013a). *Oxleas Advanced Dementia Service: Supporting carers and building resilience*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/oxleas-advanced-dementia-service (accessed on 30 September 2013).
- Sonola L, Thiel V, Goodwin N, Kodner D (2013b). *South Devon and Torbay: Proactive case management using the community virtual ward and Devon Predictive Model*. London: The King's Fund.
- Thiel V, Sonola L, Goodwin N, Kodner D (2013a). *Midhurst Macmillan Community Specialist Palliative Care Service: Delivering end-of-life care in the community*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/midhurst-macmillan-community-specialist-palliative-care-service (accessed on 30 September 2013).
- Thiel V, Sonola L, Goodwin N, Kodner D (2013b). *Pembrokeshire: Community care closer to home*. London: The King's Fund.
- Thiel V, Sonola L, Goodwin N, Kodner D (2013c). *The Esteem Team: Co-ordinated care in the Sandwell Integrated Primary Care Mental Health and Wellbeing Service*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/esteem-team (accessed on 30 September 2013).
- Tsai AC, Morton SC, Mangione CM, Keeler EB (2005). 'A meta-analysis of interventions to improve care for chronic illness'. *The American Journal of Managed Care*, vol 11, no 8, pp 478–88.
- Van Houdt S, Heyrman J, Vanhaecht K, Sermeus W, De Lepeleire J (2013). 'An in-depth analysis of theoretical frameworks for the study of care coordination'. *International Journal of Integrated Care*, vol 13, April–June.

IMPROVING CARE FOR PEOPLE WITH LONG-TERM CONDITIONS



A review of UK and international frameworks



FOREWORD

In January 2005, the government launched a bespoke NHS and Social Care Model designed to help local health and social care organisations improve care for people with long-term conditions. This model builds on successes, experiences, and innovations in the UK and elsewhere and focuses on helping health and social care communities use the tools they already have to develop a targeted systematic approach to care for people with long-term conditions.

The White Paper 'Our Health, Our Care, Our Say: a new direction for community services,' released in 2006, lays out the Government's vision for community-based care. It builds upon broader public sector reforms, helping people to live more independently and to exercise greater personal choice. In order to achieve this, people will look for greater flexibility in service provision, improved accessibility, more timely interventions, a broader range of service providers from whom they can choose their care, and care closer to home with minimal disruption to their daily lives.

This all requires a significant 'shift' in the way care is delivered, away from a reactive 'one size fits all' approach, often delivered in a hospital setting, towards a community based, responsive, adaptable, flexible service. This is far more than simply changing the location where care is delivered, and requires a significant whole system change. Not only do we need to support the shift in the location of delivery, but also the behavioural change of both service users and providers to deliver sustainable improvements in line with the White Paper's vision.

The overall vision goes some way to describing the methods for achieving this. The NHS Institute for Innovation and Improvement's Primary Care/Long Term Conditions Priority Programme aims to work with a range of field test sites to establish how far this vision has been adopted within local communities, to further develop the how to deliver a shift of care (across a range of themes) and how to accelerate this change, for learning, adoption and spread across the NHS. Within the framework of the NHS and Social Care Model, the field sites will be reviewing and fundamentally redesigning the process of care for those with long-term conditions so that the system fits around the person, rather than the person fitting within the system.

This evidence review was commissioned as an early part of the NHS Institute's workplan to help us gain a greater understanding of current international, national, and local thinking about the different approaches in use. We want to develop high-impact approaches, based on best evidence of 'what works.' This review suggests that there is a great need to test different approaches, understand which factors make the biggest difference, and spread the knowledge widely. We are making the review available because we hope that local care communities will find the information useful background material as they continue to implement the NHS and Social Care Model and the White Paper.

Gary Lucking
Head of Primary Care/Long Term Conditions Programme
NHS Institute for Innovation and Improvement

Acknowledgements

This review was conducted by Debbie Singh and Chris Ham.

Debbie Singh is an independent researcher and evaluator, working with the NHS, local authorities, universities, and charities. Debbie led the review of models of chronic care, searching databases, contacting authors of relevant studies, and writing up the results; developed the questionnaire for the SHA survey and responded to enquiries from SHAs; and wrote and edited the report.

Chris Ham is Professor of Health Policy and Management at the University of Birmingham Health Services Management Centre. Chris developed the idea for the study in conjunction with the NHS Institute for Innovation and Improvement, liaised with the commissioners of the report, and led the survey of Strategic Health Authorities.

We would like to thank Strategic Health Authorities and Primary Care Trusts throughout England for contributing to this review, colleagues in the UK and abroad that we contacted for information; and Ed Wagner and Rafael Bengoa for providing feedback on a draft of the report.

We would also like to thank publishers for allowing us to reproduce diagrams. Copyright permissions are listed on page 35.

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A REVIEW OF UK AND INTERNATIONAL FRAMEWORKS

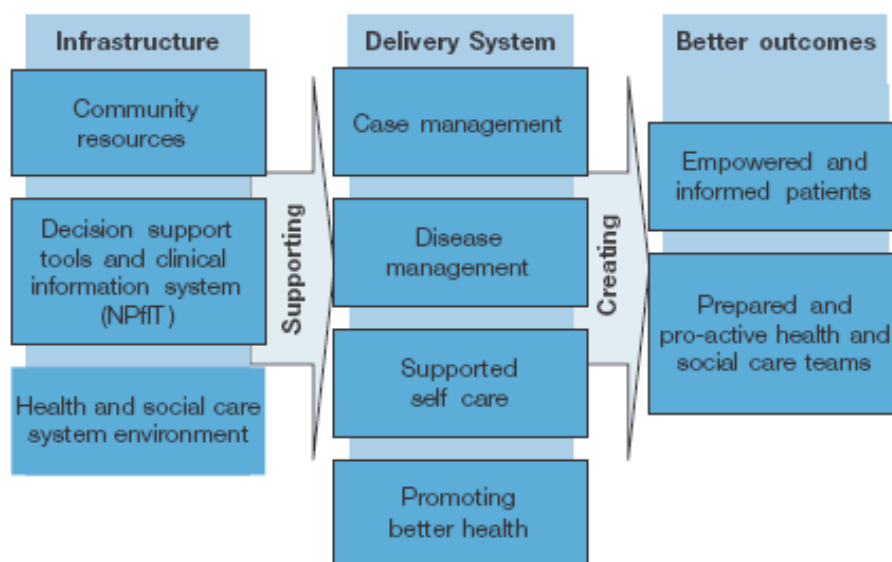
SECTION 1: BACKGROUND

In Britain, six out of ten adults report having a long-term condition that cannot currently be cured - and people with long-term illnesses often suffer from more than one condition, making their care even more complex.¹ Eighty percent of primary care consultations and two thirds of emergency hospital admissions in the UK are related to long-term conditions.¹

"Chronic disease represents a significant and exciting challenge for the NHS. Good chronic disease management offers real opportunities for improvements in patient care and service quality, and reductions in costs."²

Supporting People with Long-term Conditions, published January 2005, set out the government's plans to help people with long-term conditions live healthy lives³ and introduced the NHS and Social Care Model. This model outlines how people with long-term conditions will be identified and receive care according to their needs; how the *Expert Patients Programme* will be expanded throughout England to promote self-management; how specialist nurses (community matrons) will support people with complex conditions; and how teams of staff will be encouraged to work together with people with long-term conditions and their families.

The NHS and Social Care Model⁴



The key facets of the NHS and Social Care Model are:

- a systematic approach that links health, social care, patients and carers,
- identifying everyone with a long-term condition,
- stratifying people so they can receive care according to their needs,
- focusing on frequent users of secondary care services,
- using community matrons to provide case management,
- developing ways to identify people who may become very high intensity service users,
- establishing multi-disciplinary teams in primary care, supported by specialist advice,
- developing local ways to support self care,
- expanding the Expert Patient Programme and other self-management programmes,
- and using tools and techniques already available to make an impact.

AIMS

The NHS and Social Care Model was developed based on examples of good practice in the UK and abroad. Other similar frameworks are being implemented throughout the world.

The NHS Institute for Innovation and Improvement has been commissioned to identify ways to help the NHS shift care out of hospitals and into significantly redesigned community based systems, focusing on the management of long-term conditions. This work will support the ongoing implementation of the NHS and Social Care Model and the Our Health, Our Care, Our Say White Paper.

As a starting point for this work, the NHS Institute wanted to compile up to date information about other generic care models and the impact of these models. Therefore this report describes some of the key frameworks used to conceptualise chronic care in the UK and abroad and summarises evidence about the effects of these frameworks.

Our three key questions were:

- What frameworks for people with long-term conditions have been used internationally?
- What evidence is there about the impacts of these frameworks?
- What approaches have been adopted by Strategic Health Authorities?

We defined a 'framework' as an overarching approach that describes the different elements needed to care for people with long-term conditions most effectively. We did not focus on particular local interventions. Instead the focus was on 'higher level' strategic frameworks that outlined multiple interlinked components.

The review describes frameworks for working with people with long-term conditions generally, rather than evidence about approaches to specific conditions.

IDENTIFYING FRAMEWORKS

We used three methods to review chronic care frameworks in the UK and abroad:

1. a rapid review of published and unpublished literature,
2. feedback from experts in the field,
3. a survey of all Strategic Health Authorities in England.

Reviewing literature

We searched 17 electronic databases for published and unpublished reports about broad conceptual frameworks for providing care for people with long-term conditions. One reviewer searched MEDLINE, Embase, ERIC, Ovid, Cinahl, the Science Citation Index, the Cochrane Library and Controlled Trials Register, PsychLit, HealthStar, the WHO library, Health Management Information Consortium, Sigal, ReFeR, Dissertation Abstracts, NRR Research Registers, ASSIA and HMIC for information available as at December 2005.

Search terms included combinations of:

- generic terms (chronic care; model; framework; care model; long-term condition; elements; multidisciplinary, interdisciplinary, partnership, shared care, joint working, collaborative, disease management, care management; networks; pathways);
- names of models and organisations (CCM; WHO; ICCG; IHI; Kaiser; EverCare; Pfizer);
- and conditions and associated synonyms (asthma; diabetes; hypertension; arthritis; heart failure; stroke; cardiac; dementia; mental health; depression and so on).

Mesh terms and expanded keyword searches were used where available.

We also hand searched selected journals, websites, and the bibliographies of identified articles for additional material.

We included descriptive articles outlining components of any named or unnamed model plus studies of any design that assessed the impacts of these frameworks. When assessing impacts we prioritised systematic reviews and randomised trials published between 1995 and 2005. However, in instances where trials were not available, studies lower in the 'hierarchy of evidence' were included. Using this hierarchy of evidence allowed the reviewers to focus on the highest quality research, whilst not excluding lower quality studies when there was where a paucity of evidence.

Any documents or websites available only in a language other than English were translated - by the original authors where possible.

All impact studies were checked for validity and relevance by one reviewer, using the methodology of the Cochrane Collaboration and the NHS Centre for Reviews and Dissemination.

One reviewer extracted data about frameworks and their impacts. To synthesise material, one reviewer grouped studies according to topic areas and outcomes and provided a narrative summary of key trends. Meta-analysis was not possible given the heterogeneity of evidence about each model and the paucity of evidence about most frameworks.

Feedback from experts

We contacted more than 100 experts in the field and authors of identified papers to see whether they knew of any additional frameworks or unpublished material. We contacted experts from governments and health organisations in Australia, Canada, France, Germany, Italy, New Zealand, Turkey, the US and the UK as well as organisations such as WHO, European Observatory on Health Systems and Policies, RAND, US Institute for Healthcare Improvement, US National Institutes for Health, Kings Fund, NHS Centre for Reviews and Dissemination, UK National Centre for Primary Care Development, and universities. Any material identified by experts in the field was assessed for relevance and validity by one reviewer and included in the evidence summary if appropriate.

Surveying Strategic Health Authorities

To gain feedback about the approaches implemented by Strategic Health Authorities (SHAs) in England we designed a simple questionnaire and posted and emailed the survey to all 28 SHAs. We targeted representatives from the SHA Long-term Conditions Network and those with responsibility for chronic care and older people's services. We telephoned and emailed reminders to all SHAs and followed up some SHAs with more detailed interviews where required.

Twenty out of 28 SHAs responded (71%). We analysed the feedback by synthesising key trends.

CAVEATS

When interpreting the evidence about key frameworks overleaf, it is important to bear in mind the following caveats.

- The review focused on readily available literature and feedback and was completed within a three week period. It is not a systematic appraisal of all material in this field.
- There are many descriptions of service delivery models, but fewer outlines of underlying thinking. Service delivery models may be underpinned by theoretical frameworks, but if those frameworks were not explicit, they were not included in this review.
- Many impact assessments do not assess the mechanisms by which components of a framework or model interact. The lack of comparative evidence makes it difficult to draw conclusions about the extent to which certain components of a framework are essential.
- In practice, not all components of a particular framework may be implemented consistently. Theoretical models provide guidance about components for practitioners to consider, but it is difficult to assess the effectiveness of different models because the models themselves will be interpreted and applied in varying ways by different practitioners.
- A lack of comparative evidence does not mean that there are no differences between frameworks. Nor does a lack of research or 'naming' of certain frameworks necessarily mean that unnamed models are not effective for people with long-term conditions.
- The context in which frameworks are implemented influences outcomes. Much of the available evidence is sourced from countries with very different healthcare economies and styles of working to the United Kingdom. On a related note, some studies have compared new models with 'usual care.' What comprises 'usual care' in one country or location may be very different from usual care in another context, but most studies do not define the components of usual care in any detail.

SECTION 2: INTERNATIONAL MODELS

This section outlines international frameworks, including those that helped to inform the development of the NHS and Social Care Model. It covers:

- broad theoretical frameworks for providing care for people with long-term conditions,
- models for delivering selected components of these frameworks (delivery models),
- and examples of approaches being applied in some developed countries.

BROAD FRAMEWORKS

The Chronic Care Model

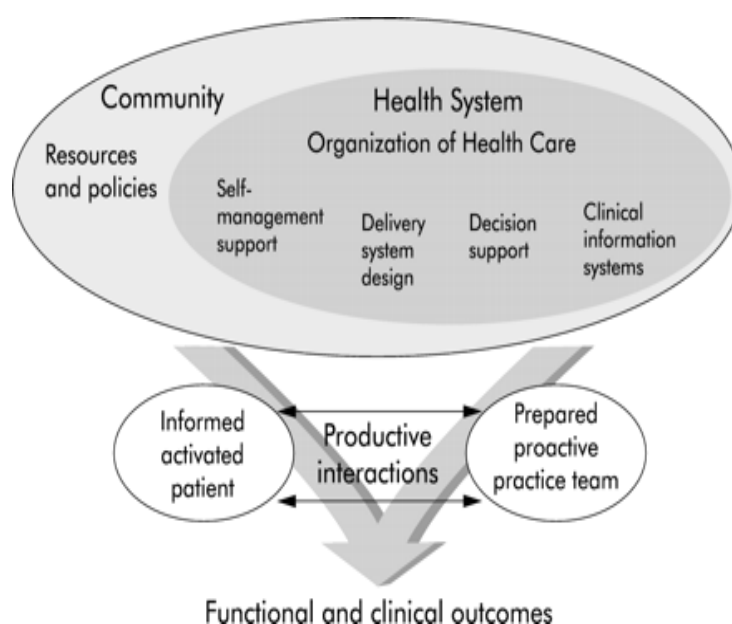
The Chronic Care Model is perhaps the best known framework about care for people with long-term conditions. The model focuses on linking informed, active people with long-term conditions with pro-active teams of professionals. It acknowledges that a substantial portion of chronic care takes place outside formal healthcare settings and suggests that six elements are of central importance in initiatives to improve chronic care: community resources; the healthcare system; patient self-management; decision support; delivery system redesign; and clinical information systems.⁵ The components of the model are based on research evidence.

The key principles of this model include:⁶

- mobilising community resources to meet the needs of people with long-term conditions,
- creating a culture, organisation, and mechanisms that promote safe, high quality care,
- empowering and preparing people to manage their health and healthcare,
- delivering effective, efficient care and self-management support,
- promoting care that is consistent with research evidence and patient preferences,
- and organising patient and population data to facilitate efficient and effective care.

Developed by Ed Wagner and his team in the US in 1998, this model has been implemented in numerous settings.^{7,8,9,10,11,12} In fact, most chronic care policies in developed countries now draw on this model to some extent.

The Chronic Care Model¹³

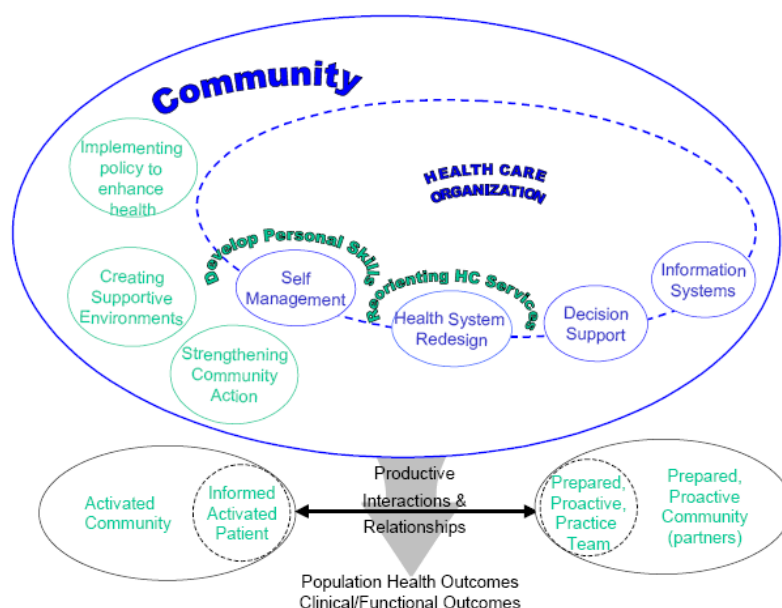


Examples of service delivery components of the Chronic Care Model¹⁴

Based on pilot testing and published evidence, in 2003 the model was revised to include cultural competency, patient safety, care coordination, community policies, and case management. The revised model is sometimes referred to as the 'Care Model'.¹⁵

A number of countries have adapted or added to the Chronic Care Model. For example, in Canada policy makers felt that the Chronic Care Model was focused on clinically oriented systems, making it difficult to apply to prevention and health promotion activities. A Health Authority in Vancouver helped to conceptualise the "Expanded Chronic Care Model" which includes population health promotion components such as the social determinants of health and enhanced community participation.¹⁶ Similarly, the US Veteran's Affairs model adds a health promotion and prevention component to elements of the Chronic Care Model.

The Expanded Chronic Care Model¹⁷



Is the Chronic Care Model effective?

"The chronic care model is not a quick fix or a magic bullet; it is a multi-dimensional solution to a complex problem."¹⁸

We reviewed 44 studies about the effects of the Chronic Care Model. We found no studies comparing the effects of the original and the Expanded Chronic Care Model or the 'Care Model.'

The Chronic Care Model was developed based on reviews of best practice and high quality evidence. For example, a Cochrane systematic review of hundreds of studies suggested a synergistic effect when individual interventions (components of the model) are combined.¹⁹ However until recently, the Chronic Care Model had not been evaluated in controlled studies.²⁰ Observational studies reported better processes, outcomes, or costs in individual organisations adopting the Chronic Care Model, but such studies do not tell us whether the model is more effective than others.^{21,22,23,24,25,26,27,28}

Therefore a formal evaluation programme was set up in the US to assess the effects of the Chronic Care Model. RAND led a four-year study of three collaboratives with more than 40 US organisations implementing the model. Although the findings are still being analysed, the evaluators suggest that successful implementation of the Chronic Care Model can lead to better processes and outcomes of care, including clinical outcomes, satisfaction, and costs.^{29,30,31} These trends seem to hold for adults and children³² with conditions such as asthma,^{33,34} diabetes,³⁵ heart failure,³⁶ and depression.³⁷

However RAND investigators found that quality improvement initiatives were implemented to varying degrees by each organisation and that organisations focussed more on some components of the model than others.³⁸ Four components of the model were most likely to be associated with sustained change: organising practice teams; collaborative decision making with people with long-term conditions; encouraging provider participation in improvement efforts; and de-emphasising traditional patient education.³⁹

A number of literature reviews have also been undertaken about components of the Chronic Care Model. The most recent is a meta-analysis of 112 studies. The authors concluded that interventions incorporating at least one element of the Chronic Care Model are associated with improved outcomes and care processes for people with asthma, diabetes, heart failure, and depression. Only people with heart failure and depression consistently had improved quality of life.⁴⁰

The reviewers also assessed whether any elements of the model are essential for improving outcomes. They found that:

- no single element of the Chronic Care Model was essential for improving outcomes;
- changes to delivery system design significantly improved processes and outcomes;
- self-management support significantly improved processes and outcomes;
- decision support improved care processes, but not outcomes;
- there were no significant benefits from clinical information systems.

There was insufficient evidence about community resources and organisational elements.

These findings are important because they attempt to analyse exactly which components of the model may have most benefit.

Another review found that programmes based on the Chronic Care Model may improve patient and staff satisfaction, quality of care, and clinical outcomes, and reduce resource use in some cases. However, the reviewers concluded that it was difficult to distinguish which components of these programmes may be most effective.⁴¹

Quality of care

The Chronic Care Model is often implemented as part of a broad disease management programme. In addition to the studies outlined above, we identified six reviews about the impacts of broad programmes which included components of the Chronic Care Model.^{42,43,44,45,46,47} The totality of evidence suggests that applying components of this model may improve quality of care for people with many different long-term conditions, but it remains uncertain which components are most effective or transferable.

Clinical outcomes

Evidence about effects on clinical outcomes is varied. While some systematic reviews suggest improved functional status and reduced risk of hospital admission,⁴⁸ others have found only small benefits.⁴⁹ Unpublished documents from the US RAND evaluation suggest improved clinical outcomes in people with diabetes, heart failure, and asthma.⁵⁰

There is still debate about whether all components of the Chronic Care Model impact on clinical outcomes. An observational study of 17 US clinics using the Chronic Care Model to improve diabetes care found that delivery system redesign was the only factor linked to improved clinical outcomes. Self-management support and clinical information systems had no significant impact on clinical outcomes.⁵¹ A similar study found that activities initiated by practitioners and managers and an organisational commitment to quality improvement were the two most important components of the model.⁵²

Resource use

There is evidence that implementing the Chronic Care Model can reduce healthcare resource use. We identified a number of reviews to this effect.^{53,54,55} One review found that in 18 out of 27 studies of long-term conditions such as congestive heart failure, asthma, and diabetes, components of the Chronic Care Model were associated with reduced healthcare costs or reduced use of healthcare services.⁵⁶ Cost-effectiveness analyses from developed countries throughout the world support these findings.^{57,58} However, there are some dissenting views. For example, a randomised trial in ten US community hospitals found that regional collaboration with quality improvement and disease management programmes had no significant effect on clinical outcomes or healthcare resource use.⁵⁹

Caveats

In fact, a literature review for the World Health Organisation (WHO) found that while broad chronic care programmes may improve health professionals' adherence to evidence-based standards of care, there was no strong evidence about which components of these programmes may impact on the quality of care provided. Nor did WHO find evidence of a direct link between broad chronic care programmes and reductions in mortality, improvements in quality of life, or cost-effectiveness.⁶⁰ Also, even the most effective interventions based on the Chronic Care Model tend to have modest effects.⁶¹

Much research is not 'high quality' evidence. There are randomised trials of specific components of the Chronic Care Model, such as patient education or self-management, but there have been few high quality studies assessing the impact of this overall framework. Those studies that do exist tend to have relatively small samples, be industry-sponsored, or be observational studies rather than randomised trials.^{62,63,64,65} Most available evidence is drawn from the US, although recent studies from Europe, Canada, and Australia tend to support these trends.

In summary, there is extensive evidence about each component of the Chronic Care Model, but less is known about how this model compares with others in terms of effectiveness. This is largely because few other clearly distinct models exist for comparison.

While there is evidence that single or multiple components of the Chronic Care Model can improve quality of care, clinical outcomes, and healthcare resource use, it remains unclear whether all components of the model, and the conceptualisation of the model itself, is essential for improving chronic care.

Innovative Care for Chronic Conditions Model

The Chronic Care Model may be conceptualised from a primary care perspective. In 2002 WHO adapted this model to focus more on community and policy aspects of improving chronic care.

The Innovative Care for Chronic Conditions Model focuses on improving care at three different levels: micro level (individual and family), meso level (healthcare organisation and community), and macro level (policy).⁶⁶

The Innovative Care for Chronic Conditions Framework⁶⁷



At the centre of the Innovative Care for Chronic Conditions Framework is the micro level, consisting of people with long-term conditions, families, community partners, and the healthcare team. The model suggests that positive outcomes for people with long-term conditions occur only when people and their families, community partners, and health professionals are informed, motivated, and working together. The micro level is supported by healthcare organisations and the broader community, which in turn influence and are impacted on by the broader policy environment. In this model, essential elements for the policy environment include leadership and advocacy; integrated policies that span different disease types and prevention strategies; consistent financing; developing human resources; legislative frameworks; and partnership working.

Like the Chronic Care Model, there is evidence that specific components of the Innovative Care for Chronic Conditions Framework can improve some processes and outcomes.⁶⁸ However we identified no review, trial, or observational study that explicitly attempted to assess the effectiveness of the Innovative Care for Chronic Conditions Framework and no rigorous evidence about the value of a policy focus.

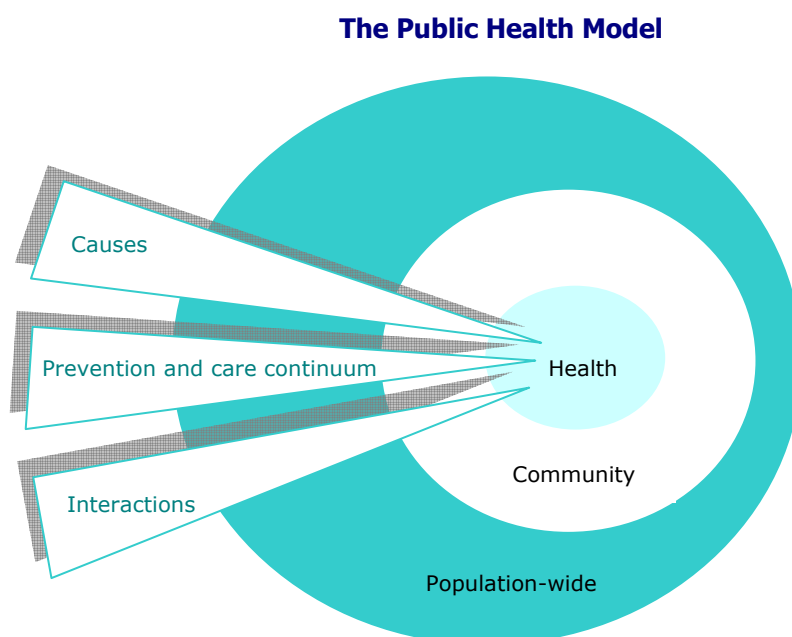
Public Health Model

Similar to the Innovative Care for Chronic Conditions Model is the Public Health Model for chronic conditions developed in the US in the early 2000s. Although this is not a well known model, it received some attention in journal articles.⁶⁹

The underlying principle of the Public Health Model is that in order to impact on the burden of chronic conditions, there must be three levels of intervention:

- population-wide policies,
- community activities,
- and health services.

Health services include both preventive services and ongoing care for people with chronic conditions. The model suggests that it is important to identify and address interactions between and among the three levels of action.



The Public Health Model is a systems-wide perspective which includes the continuum of prevention and care. It emphasises the determinants of disease as well as social, cultural, and economic factors that might impinge on the quality and quantity of care.

Furthermore a Public Health Framework in the US suggests that the following elements are critical to the success of chronic care programmes:⁷⁰

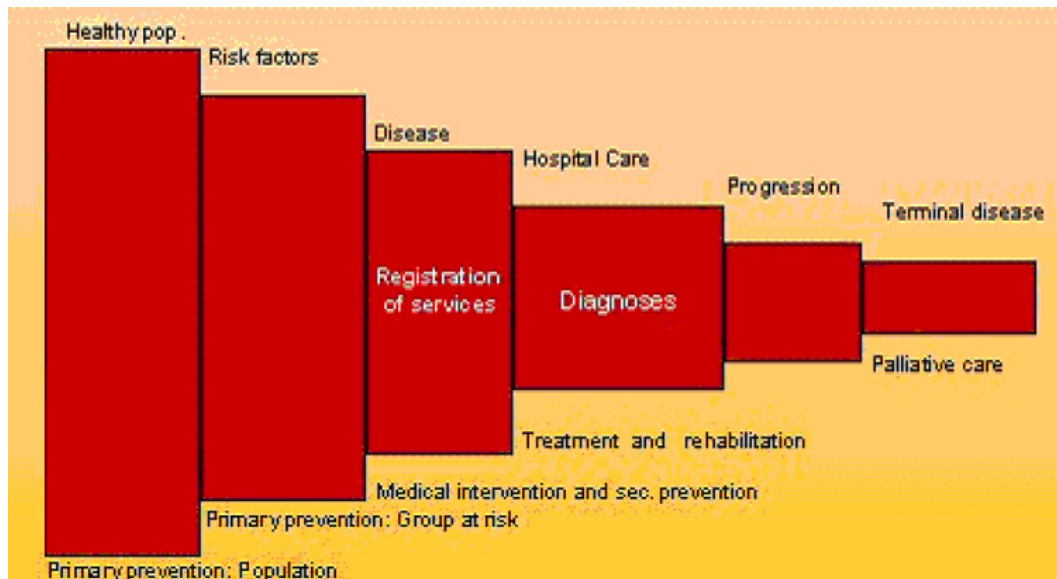
- leadership,
- epidemiology and surveillance,
- partnerships,
- state plans,
- targeted interventions in various settings,
- evaluation,
- programme management and administration.

Although there are evaluations of individual public health initiatives, we identified no study of the implementation of the Public Health Model and no evidence of its effectiveness.

The Continuity of Care Model

The Continuity of Care Model outlines how chronic conditions develop in response to risk factors in the community and suggests points at which to target prevention efforts, medical intervention, treatment and rehabilitation, and palliative care. It was conceptualised in the 1990s.

The Continuity of Care Model⁷¹



This model tracks chronic care from the general population (left of diagram); through people who develop one or more long-term conditions following exposure to risk factors; through to people who have terminal disease (right of diagram). The model suggests the need for different prevention schemes, treatment, rehabilitation, and palliative care at varying stages of the disease pathway.

Adaptations of this model have been applied to emphasise the role of rehabilitation⁷² and to conceptualise neurological conditions.⁷³ Other models are based on similar principles, including the Life Course Model.⁷⁴

We identified few studies of implementing the Continuity of Care Model. One observational study in Australia reported implementing the model in an Extended Care Centre for older people. The authors noted the model was associated with reduced length of stay, better teamwork and staff morale, and systemic adaptations in other parts of the healthcare sector.⁷⁵ However, no more rigorous evidence was identified.

Although there are evaluations of individual interventions that prioritise continuity, we identified no high quality studies of the implementation of the Continuity of Care Model.

EXAMPLES OF SERVICE DELIVERY MODELS

As well as broad theoretical frameworks, models have been developed which focus on the most effective ways to deliver services for people with long-term conditions. These service delivery models target specific components of the broad frameworks outlined above or target people at greatest risk of hospitalisation.

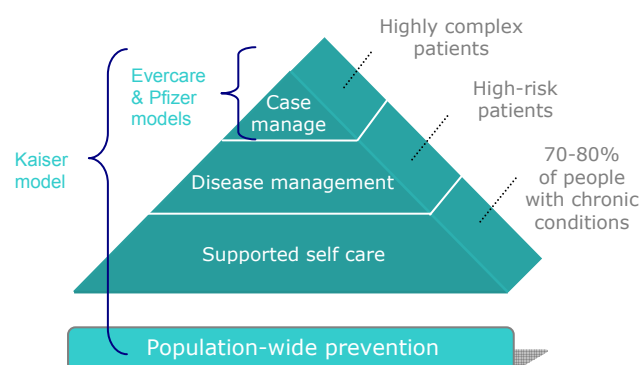
This section describes selected examples of service delivery models. The aim is not to provide a systematic overview of all existing models, but rather to give a flavour of some of the most commonly referred to models.

Kaiser, EverCare, and Pfizer approaches

Three commonly discussed service delivery frameworks for supporting people with long-term conditions are the approaches developed by Kaiser Permanente, EverCare (United Healthcare), and Pfizer in the US. These approaches are not mutually exclusive. All share a proactive approach to managing care for people with long-term conditions.

Their major distinguishing features are that the Kaiser model focuses on integrating services and removing distinctions between primary and secondary care for people at all stages of the 'Kaiser pyramid' whereas the Evercare and Pfizer approaches focus on targeting those at highest risk of hospitalisation.

The 'Kaiser Triangle' illustrating different levels of chronic care



The approach taken by Kaiser Permanente is based on the Chronic Care Model.⁷⁶ Kaiser focus on integrating organisations and disciplines. Doctors from primary and secondary care share the same budget and function within multi-speciality centres which also house nurses, pharmacists, laboratory technicians, radiology staff and others. People with long-term conditions are stratified according to need, with intensive management targeted at those at highest risk.⁷⁷

United Healthcare's EverCare model targets people at highest risk using Advanced Primary Nurses as case managers (similar to community matrons). Here the focus is on integrating social and healthcare to meet an individual's needs. Once older people at high risk have been identified, Advanced Primary Nurses assess their care needs and coordinate their journey along a care pathway. The aim is to maintain health, detect changes and prevent unnecessary admissions, and facilitate early discharge when admissions occur.⁷⁸

The Pfizer approach also targets those at highest risk, using telephone case management to supplement existing services.

All of these service delivery models include some form of case management as a component of care. A wide range of other case management frameworks have been described, ranging from social models to medical models.^{79,80,81}

Key characteristics of selected service delivery models⁸²

	Kaiser approach	EverCare approach	Pfizer approach
Overall essence	Uses a wide mix of strategies to target the whole care continuum, focussing on integrated services	Uses specialised nurses to individually support those people at highest risk of hospital admission	Uses telephone system to monitor and refer people at highest risk
Key principles	<ul style="list-style-type: none"> Unplanned hospital use is an indicator of system failure Align care to the needs of the client No boundary between primary and secondary care Patients are 'partners' in care Patients are providers of care Information is essential Improvement occurs through commitment and shared vision, not through coercion 	<ul style="list-style-type: none"> Individualised whole person approach Care provided in least invasive manner in the least intensive setting Primary care is the central organising force for all care Decisions based on data and population evaluation Avoid adverse effects of medications and poly-pharmacy 	<ul style="list-style-type: none"> Proactive contact with patients at highest risk to assess, refer, educate, and monitor Supplement to existing services (not substitute) Encourage self-treatment and behaviour modification
Key strategies			
<i>Education</i>	<ul style="list-style-type: none"> Patient education, including using the internet and during hospital stay 	<ul style="list-style-type: none"> Focused education and follow-up mentoring Self-care promotion 	<ul style="list-style-type: none"> Patient education through telephone support
<i>Target</i>	<ul style="list-style-type: none"> Whole spectrum of chronic care Includes targeted risk assessment 	<ul style="list-style-type: none"> Identifying people at high risk using 'Hospital Analysis Tool' 	<ul style="list-style-type: none"> Identifying people at high risk
<i>Care planning</i>	<ul style="list-style-type: none"> Proactive management Developing integrated care pathways to reduce inappropriate referrals to services 	<ul style="list-style-type: none"> Proactive management of people at high risk Individualised care plan Medicines management for co-morbidities 	<ul style="list-style-type: none"> Case finding Patient assessment Proactive management of people at high risk
<i>Staff</i>	<ul style="list-style-type: none"> Developing partnerships between clinicians and managers High proportion of doctors in leadership roles GPs in Accident and Emergency Departments; consultants in GP clinics; dedicated MD rounds 	<ul style="list-style-type: none"> Case management by specialised nurses ('Advanced Primary Nurses') Extended GP role through partnership with nurses 	<ul style="list-style-type: none"> Dedicated telephone support staff (nurses)
<i>Tools</i>	<ul style="list-style-type: none"> Info systems such as reminders on patient notes and monitoring systems Clinical evidence database 	<ul style="list-style-type: none"> IT risk assessment Share data and patient info across system to improve care 	<ul style="list-style-type: none"> Software for telephone case management incorporating national and local guidelines
<i>Discharge</i>	<ul style="list-style-type: none"> Online discharge summaries Dedicated discharge planners (1 per 25 patients) 	<ul style="list-style-type: none"> Single point of contact to help access services 	
Evidence	<ul style="list-style-type: none"> In California, this model is associated with improved quality of life, and fewer hospital admissions and days spent in hospital 	<ul style="list-style-type: none"> In the US this model is associated with improved quality of life, and fewer hospital admissions and bed days 	
UK trials	<ul style="list-style-type: none"> This model is being formally trialled in nine PCTs in England 	<ul style="list-style-type: none"> This model is being formally trialled in nine PCTs in England 	<ul style="list-style-type: none"> This model is being formally trialled in England

Are these models effective?

Most information about the effects of the Kaiser, Evercare, and Pfizer approaches is drawn from the US. For example, an evaluation of the Evercare programme in the US found that this model reduced hospitalisations by focusing resources on those most at risk of hospitalisation⁸³ and could save thousands of pounds per year for each nurse employed.⁸⁴

Adaptations of the Kaiser, Evercare, and Pfizer models are all being trialled in England, as are other adaptations including 'Pursuing Perfection' initiatives.⁸⁵

Nine primary care trusts are working with United Healthcare to implement the EverCare programme, focussing on 'proactive care for the most vulnerable.' This programme aims to avoid hospital admissions for older people by providing an integrated primary care service with advanced nurses working collaboratively with GPs.⁸⁶ The national evaluation of EverCare found that this model effectively identifies vulnerable older people, helps to provide preventive health care, and has the potential to organise care around people's needs.⁸⁷ Longer term information about potential reductions in hospital admissions is not yet available.

However a significant number of people enrolled into EverCare programmes in the UK were not frequent healthcare service users. The evaluators concluded that EverCare and other case management initiatives may identify unmet needs and increase demand on health services. They also suggested that the tools designed by EverCare were not the only ones available, and that other identification and risk stratification tools may be just as effective.⁸⁸

Nine other primary care trusts are applying the Kaiser model, focussing on reducing hospital admissions by integrating services. Case studies suggest some positive benefits.⁸⁹

Another primary care trust is working with Pfizer to implement their InformaCare® model for chronic disease management. This approach uses telephone support and evidence-based clinical guidelines to encourage people to engage with the most appropriate health services and be better informed about how to deal with their condition.⁹⁰

In the US, programmes run by Kaiser and Pfizer have both been found to reduce hospital admissions and improve co-ordination of care.^{91,92} The Pfizer and Kaiser approaches are being evaluated locally, with the help of external evaluators. We identified no detailed information about outcomes from these service delivery models in the UK.

The Strengths Model

The Strengths Model originally referred to a type of case management. It was developed in the early 1980s as an alternative to 'traditional' case management in mental health. However, it has also been proposed as a model that can be applied to service delivery in long-term care and other care for people with long-term conditions. It is drawn from social service perspectives.

The Strengths Model focuses on helping people and communities discover and develop their own talents, capacity, and interests, and on connecting them with the resources they need to achieve their goals. Some authors suggest that by drawing on people's own strengths, interventions and costs can be contained.⁹³

Although there is evidence that the Strengths Model can improve satisfaction and quality of life in mental health, we identified no studies of the effectiveness of this as a broader framework for chronic care service delivery.

The Adaptive Practice Model is a similar concept, which emphasises participatory decision-making and family-centred care. The aim is to encourage people with long-term conditions and their families to share the responsibility for decision-making with physicians. This model conceptualises the physician-individual relationship and provides a structure for analysing clinical situations and choosing clinical approaches.⁹⁴ We identified no studies of the effectiveness of this model for people with long-term conditions.

Guided Care

Guided Care is another emerging service delivery model, currently undergoing testing. This US approach has been designed for older people with multiple chronic conditions. Principles from successful initiatives have been melded into a single service delivery model. A specially trained Guided Care Nurse based in a primary care practice collaborates with primary care physicians to provide seven services for 40-60 people at high-risk:

- comprehensive assessment and care planning,
- 'best practices' for chronic conditions,
- self-management,
- healthy lifestyles,
- coordinating care,
- informing and supporting family, and accessing community resources.⁹⁵

This is similar to the Community Matron role in the NHS.

Some reports suggest that Guided Care may improve quality of life and reduce healthcare resource use.^{96,97} Although descriptions of this model are beginning to emerge, we identified no high quality evidence of its impacts.

PACE Model

The Program of All-Inclusive Care for the Elderly (PACE) is a US model of service provision and financing that aims to reduce use of hospital and nursing home care. The model focuses on elderly people attending day centres, uses an interdisciplinary team for care management, and integrates primary and specialist medical care. The key feature of this model is integration of acute and long-term care services. This allows frail older people with multiple problems to receive care from a single service organisation.⁹⁸ This is one of a number of similar health insurance provider initiatives in the US, but the PACE Model has been more well documented than most.^{99,100,101,102}

While there are numerous descriptive assessments of the PACE model,^{103,104} we found little high quality evidence about its effectiveness. One comparative analysis suggested that PACE reduced hospital admissions compared to usual care, but increased the use of nursing homes.¹⁰⁵

We have not provided descriptions of all of the service delivery models currently in use. Indeed, there are many thousands of service delivery models being implemented throughout the world, many of which are not formally named. However, the few examples we have described illustrate that service delivery models tend to focus on selected components of broad chronic care frameworks, and while evaluations of individual services are available, there is no good evidence that any particular service delivery model is more effective than another.

EXAMPLES OF MODELS IN DIFFERENT COUNTRIES

Our review found few distinct named chronic care frameworks. Whether models are named or unnamed, they tend to draw on the Chronic Care Model, usually explicitly. Some argue that relatively few provider settings are fully prepared to execute the Chronic Care Model.¹⁰⁶ Various countries have interpreted and adapted the model slightly differently.

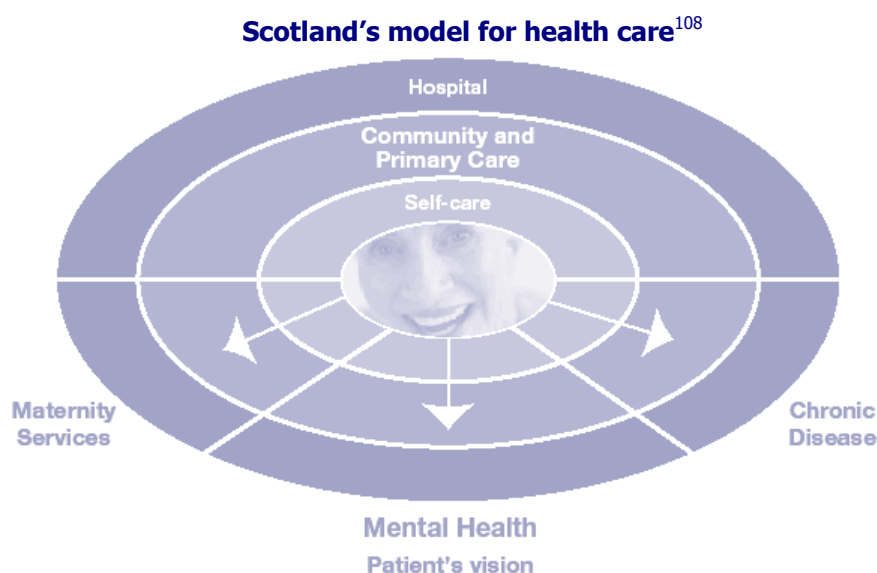
This section provides a brief description of some of the frameworks used in selected countries. Readers should bear in mind that numerous models may be implemented in each country. This section attempts to give a flavour of what is happening in different areas, rather than a systematic account of all developments. It does not explore details of health service financing and service delivery in each country.

United Kingdom

As outlined above, in England the NHS and Social Care Model was released in January 2005. We identified no evidence about the impacts of the NHS and Social Care model.

In Scotland there is an ongoing programme examining different ways to deliver chronic care. Although a formal framework for chronic care has not been conceptualised, key principles have been established. These include:¹⁰⁷

- pathways of care focussed on individuals with long-term conditions,
- partnership between professionals and people with long-term conditions,
- partnership between primary care, social care, and other agencies,
- integrated solutions that respond to the needs of people with long-term conditions,
- focus on providing care in primary care and community settings,
- and self care.



Wales has also identified effective chronic care as a key theme within recent health strategies.¹⁰⁹ There are plans to remodel services within an integrated chronic care framework over the next few years.¹¹⁰ Details of the planned model are not yet available.

Evaluations of individual interventions and service delivery models are available in England, Scotland, and Wales, but we found no descriptive or impact studies comparing the frameworks used in these countries.

Many parts of Europe have developed programmes to improve chronic care. However, apart from service delivery models, we identified no distinct chronic care frameworks.

The key principles in service delivery models in Europe appear similar to the Chronic Care Model. In particular, models have been developed that focus on nurse-led services, provide community-based or home-based care,¹¹¹ and use telemedicine.^{112,113}

The World Health Organisation rates France's health system performance as number one out of 191 countries. It has been suggested that France's attention to chronic care is one of the reasons that this country spends less than half the amount of the United States per capita on annual healthcare.¹¹⁴ The model used in France focuses on regional systems, population-based prevention, continuity of care, physician involvement in decision-making, and combining specialised medical care, assistive technology, and home support. The regional systems aim to make services more geographically accessible. However, it should be noted that the WHO's rankings are controversial, and a number of features of the health care system in France are not consistent with the Chronic Care Model.

Denmark's system involves remodelling institution-based long-term care into nationally run home-based and community-based services.^{115,116} Denmark's model combines the Expanded Chronic Care Model, the Continuity of Care Model, and the Spanish home healthcare service model.^{117,118} However we did not identify any evidence of the effects of this approach.

In Italy, service delivery has focused on care in nursing homes, and residential and outpatient services in community venues. We found no high quality evaluations of this service delivery model, but some reports suggest reduced inappropriate admissions, improved quality of life, decreased dependence on private resources, growth of voluntary services, and new occupational opportunities.¹¹⁹

In Germany, physicians initially opposed a service delivery model focussed on evidence-based guidelines and data sharing, but disease-specific programmes are now being implemented.¹²⁰ Legislation has been introduced to provide incentives for care providers to develop approaches to coordinate care for people with long term conditions and plans are in place to include new risk-adjustment mechanisms.¹²¹

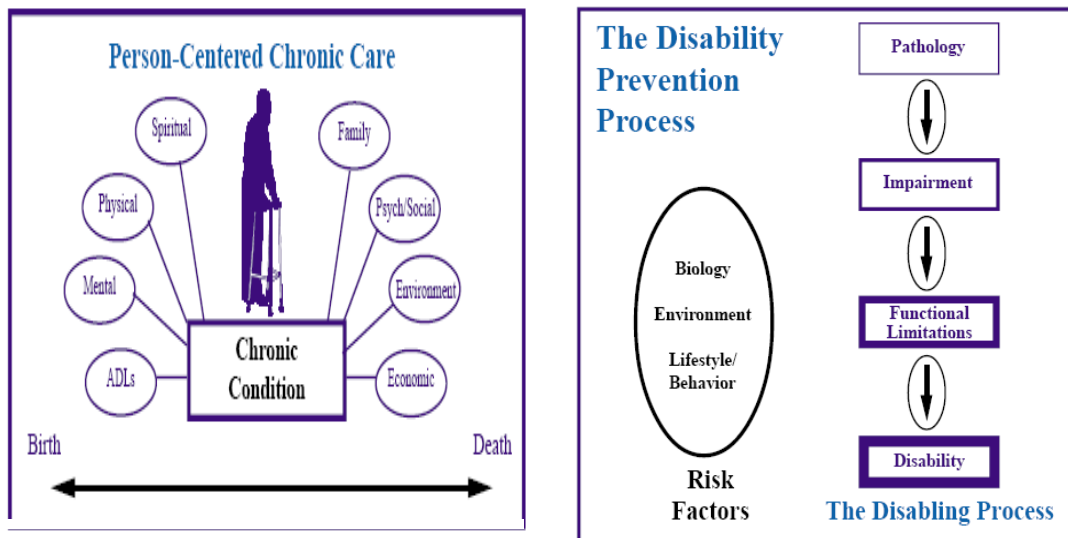
In the Netherlands, the government has been implementing components of the Chronic Care Model for at least 10 years (before the model was formally conceptualised). Their Transmural Care Programme aims to bridge the gap between hospital and community care, although there is conflicting evidence about its effectiveness.¹²²

North America

In the US, the growth of managed care in the 1990s focused on better coordination as a way to control costs and improve care for people with long-term conditions.¹²³ Prior to the conceptualisation of the Chronic Care Model, consortiums in the US were prioritising key elements of integrated care management, including:¹²⁴

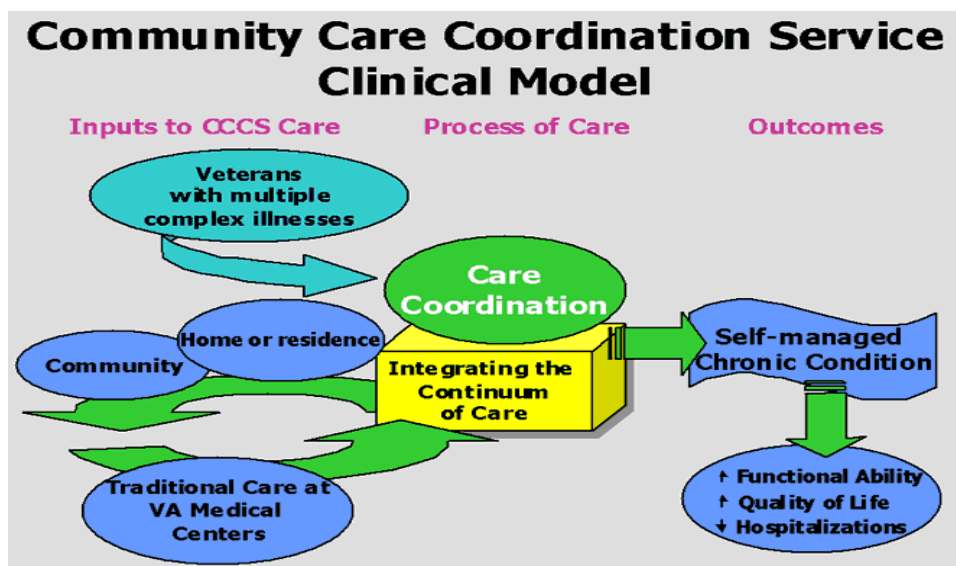
- person-centred chronic care,
- ongoing disability prevention,
- integrated services,
- targeting people at high risk,
- and using care pathways and interdisciplinary teams.

Key elements of pre-Chronic Care Model frameworks in the US¹²⁵



Most major health organisations and regions in the US have a service delivery framework designed to improve care for people with long-term conditions,¹²⁶ such as that used by the Veterans Affairs system. The majority are based explicitly on the Chronic Care Model or focus instead on one component of service delivery, such as targeting people at high risk of hospitalisation.

Veteran's Affairs Care Model¹²⁷



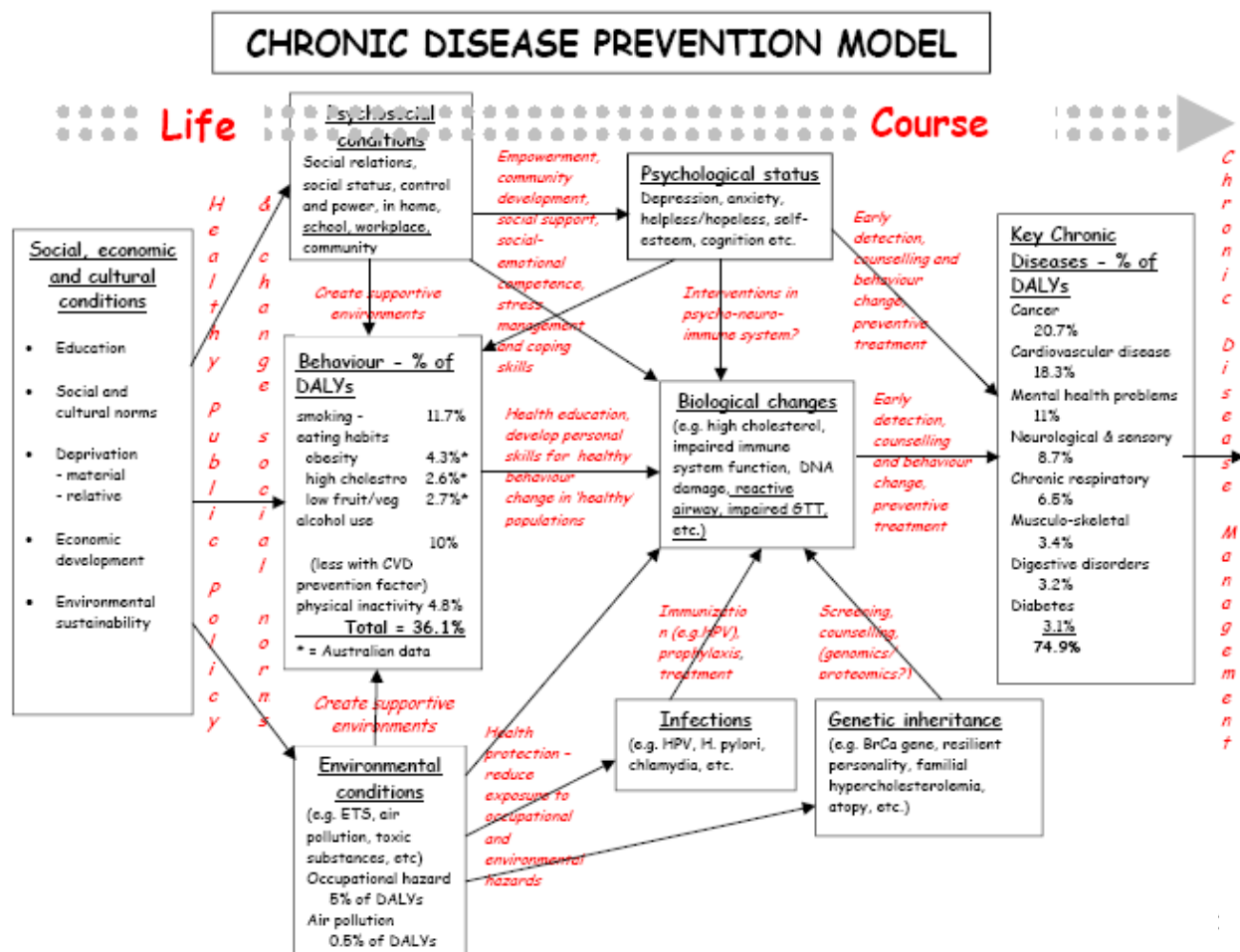
For instance, the VNS CHOICE Model in New York focuses on the principles of consumer choice; involving people with long-term conditions and their family in care planning; improving independence and functional status; collaborating with community providers and facilities to provide fully coordinated care; integrating acute and long-term care services; and collaboration between interdisciplinary care teams.¹²⁸

Another system for caring for disabled older people has been trialled in Ohio. The service model included a single point of entry to long-term care services, a telephone screen from which people could choose options, care management, and funding for extra services.¹²⁹

Another example is the Chronic Care Network for Alzheimer's Disease Model which focuses on identifying people who may have dementia, diagnostic assessment, care management, and providing information and support to caregivers.¹³⁰ Many thousands of other similar service delivery models have been implemented in the US.

Like the US, different parts of Canada have developed frameworks related to the Chronic Care Model.¹³¹ For instance, British Columbia is using an 'Expanded Chronic Care Model' which incorporates health promotion and disease prevention.¹³²

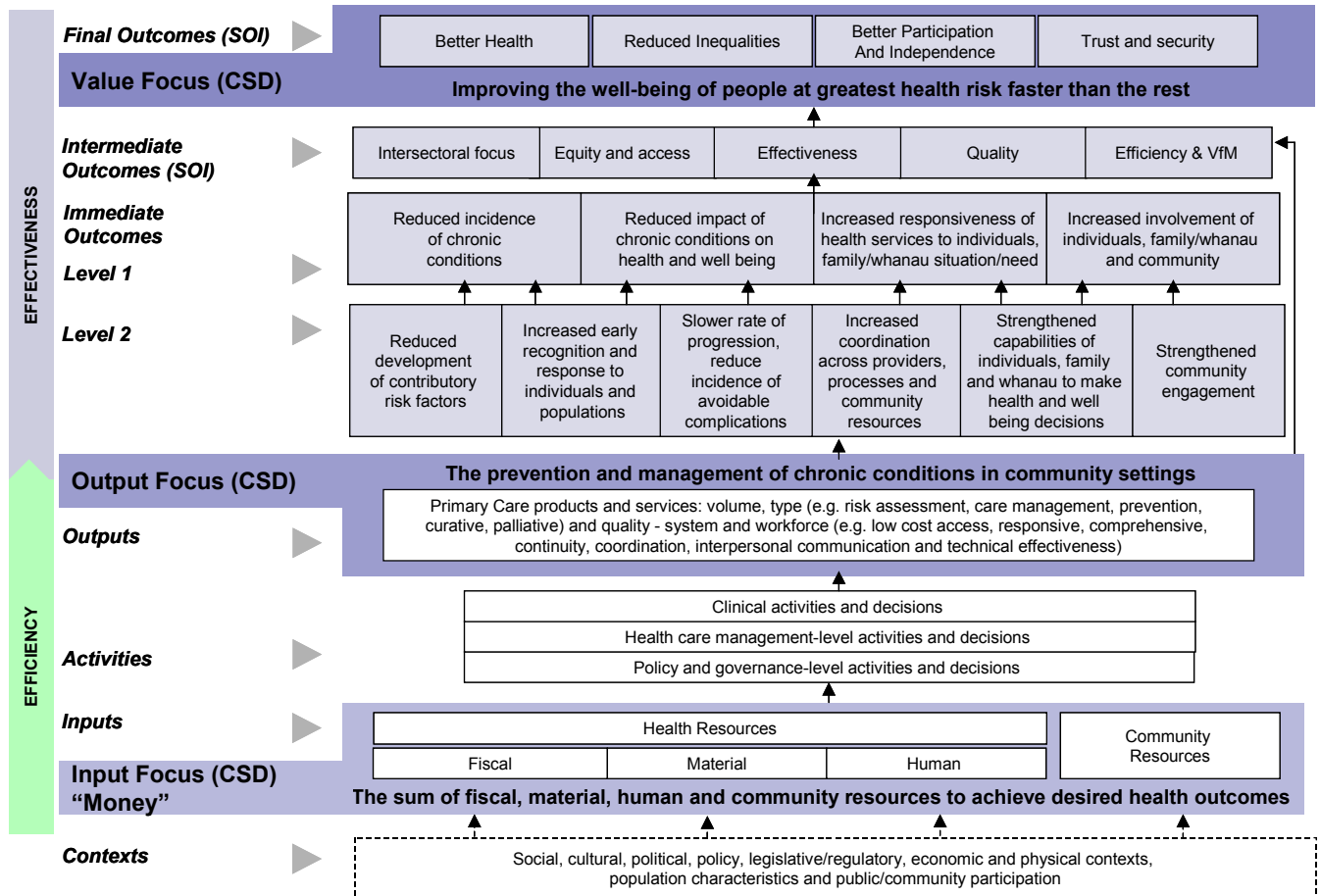
Example of a prevention model used in Canada¹³³



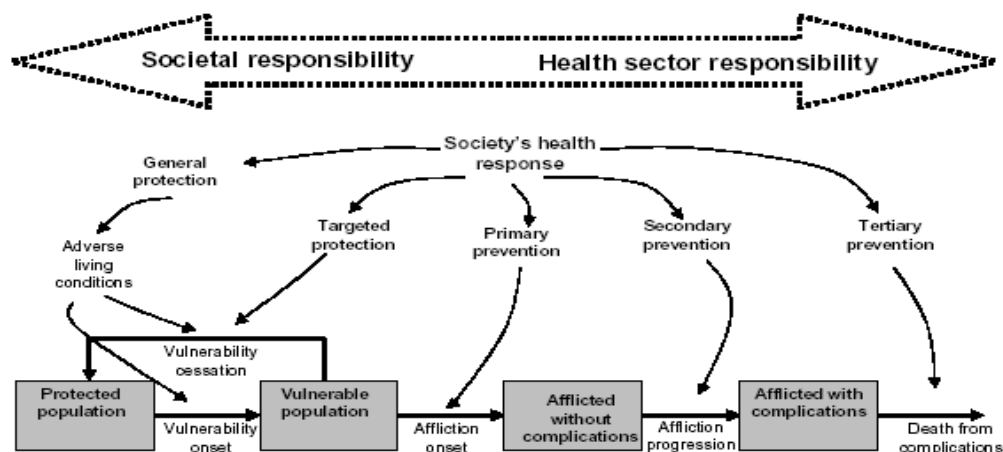
New Zealand and Australia

A number of service delivery models have been trialled in New Zealand. The New Zealand Government is using an 'outcomes intervention' approach to illustrate the relationship between aetiology, interventions, and outputs.¹³⁴ This is based on a 'Life Course' Model.¹³⁵

New Zealand's Outcomes Intervention Model¹³⁶



Example of the Life Course Model used in New Zealand¹³⁷

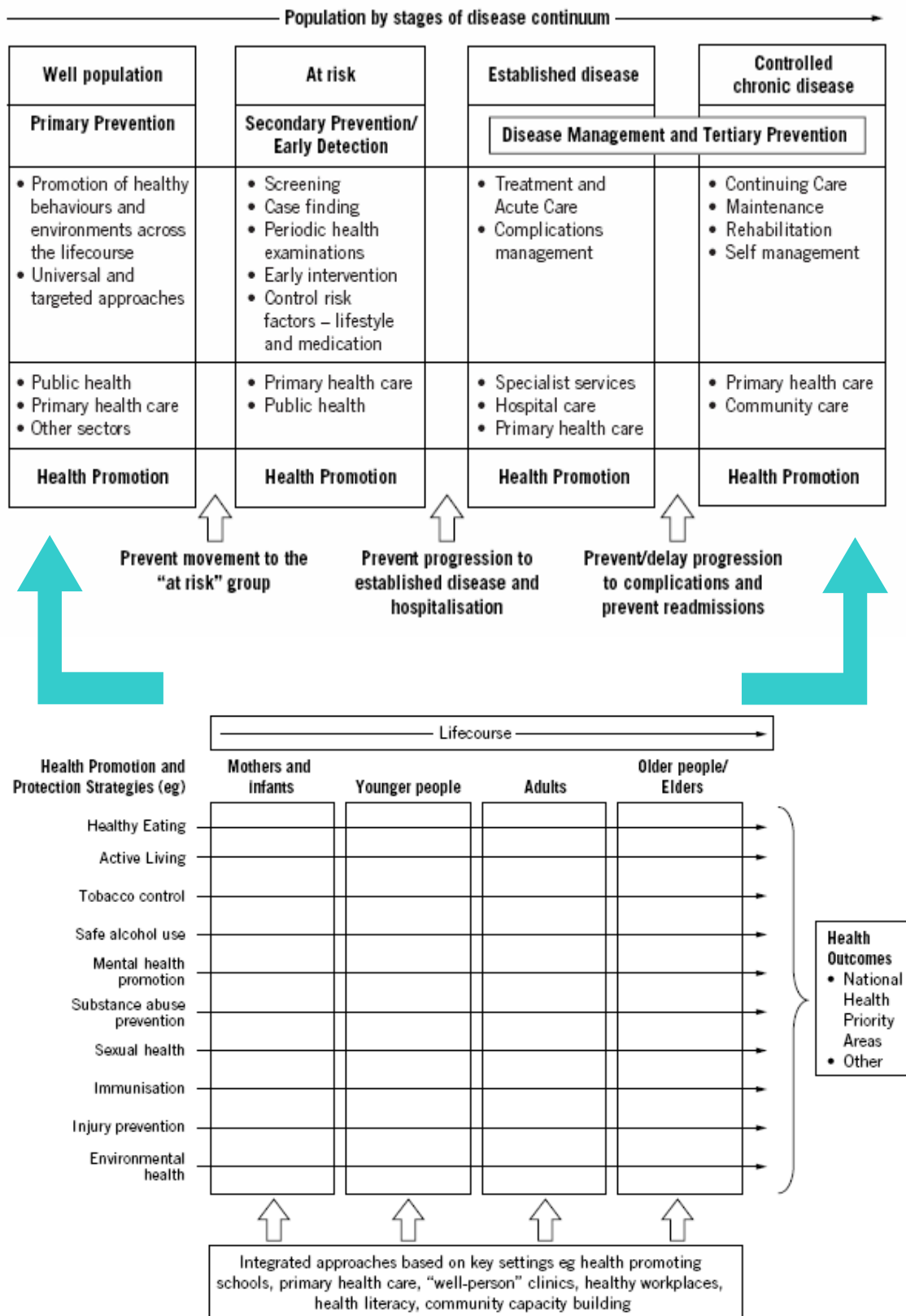


A number of specific models of care are also being trialled. For instance, the Care Plus programme, which contains some elements of the Chronic Care Model, has been tested in three primary health organisations. An evaluation found that Care Plus provides effective coordinated care from a range of health professionals.¹³⁸

The Chronic Care Management Model was trialled in one area in New Zealand. The model, which drew on the Chronic Care Model, included targeting people at high risk, organising interventions into a system of care, and using improved data storage, flags and reminders. An evaluation suggested improved health outcomes and reduced healthcare costs.¹³⁹

Various service delivery models have been trialled in different parts of Australia. A national strategy for long-term conditions is forthcoming,¹⁴⁰ and individual states have developed their own frameworks, drawing on the Chronic Care Model.¹⁴¹ A public health framework, with an emphasis on prevention and health promotion, has been in place since 2001.

Australia's national model of chronic disease prevention and control¹⁴²



Regional strategies are also in place. For example, New South Wales Health has developed a model which aims to:¹⁴³

- place people with long-term conditions at the centre of the health system,
- design services around people's unique health needs,
- develop people's capacity to participate fully in their own health care,
- develop people's capacity navigate their way through the health system,
- ensure easier and more timely access,
- have continuity of relationships between providers and between providers and patients,
- develop organisational and governance systems to support long term orientation,
- and reorientate care within the health system.

Components of chronic care clinical governance in New South Wales¹⁴⁴



Like other countries, Australia has trialled a number of new service delivery models. For instance, HealthPlus is a coordinated care model for people with multiple chronic conditions. A randomised trial found that this model improved clinical outcomes, but did not reduce healthcare costs. The model did not fully take into account organisational characteristics, environment, healthcare teams, and individual characteristics.¹⁴⁵

Asia

Service delivery models are also being developed in Asia. The government in Singapore proposed a new chronic care framework because they felt that US models focussed too heavily on managed care which may confuse healthcare professionals working in Asia.¹⁴⁶ This framework emphasises primary care and self care, but has less emphasis on organisational linkages. We found no evidence of the effectiveness of this model.

Programmes to improve care for people with long-term conditions are being implemented throughout the world, however we found no distinct chronic care frameworks in local areas. Most local models either draw heavily on the Chronic Care Model or focus on specific aspects of service delivery without explicitly outlining any underlying conceptual framework. The main point of similarity is a move to reorientate care from episodic or acute interventions towards a continuum of care which enables better prevention and management of chronic conditions.

No matter what organisational model is in place, what happens in each country seems to be based on two factors: (1) funding (not the finance system itself, but rather making funding available as an incentive to develop an organisational system); and (2) culture. Some suggest that although national policy makes a difference, it is at community level that people work together to design innovative local solutions.¹⁴⁷

SECTION 3: APPROACHES ADOPTED BY STRATEGIC HEALTH AUTHORITIES

Alongside our review of the literature and international experience, we undertook a survey of strategic health authorities (SHAs) in England to assess their approaches to chronic care. In view of the tight timetable to which we were working, the survey took the form of a short questionnaire based on the following three questions:

1. What model(s) is your SHA area using to provide or organise chronic care?
2. Why did you choose this model?
3. Is your model having any impact?

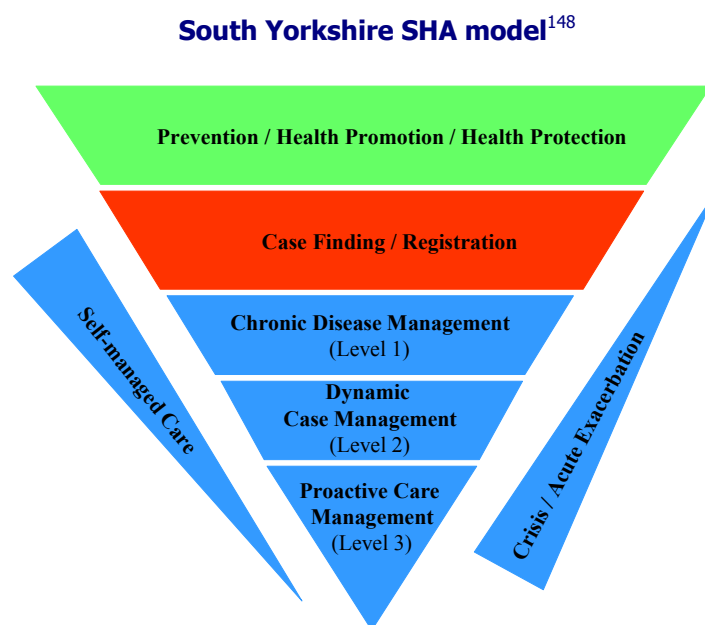
The questionnaire was emailed to SHA leads on long-term conditions on 28 November with a deadline for completion of 14 December. A hard copy of the questionnaire was posted at the same time and SHA leads were contacted by telephone a few days later to ensure the questionnaire had been received. SHAs that had not responded by the deadline were telephoned with a reminder.

We received responses from 20 of the 28 SHA areas, a response rate of 71%.

OVERVIEW OF RESPONSES

Responses to the survey varied from brief replies to each of the three questions to detailed submissions accompanied by local management papers and policy documents. Sixteen of the 20 responses came from SHA leads on long-term conditions or their colleagues (80%) with the remaining four taking the form of replies from individual PCTs from within the SHA areas.

All of the responses emphasised that the main responsibility for leadership on long-term conditions rests with PCTs rather than SHAs. In six cases, it was reported that an SHA-wide model has been adopted to support PCTs (30%). In South Yorkshire, for example, the SHA is using an inverted version of the Kaiser triangle.



Dorset and Somerset SHA has also adopted an SHA-wide approach, set out in its document: A Strategic Framework for the Development of Services for People with Long Term Conditions. The framework uses the Kaiser triangle to identify three levels of care. A similar approach was reported by Leicestershire, Northamptonshire and Rutland SHA.

The Transforming Chronic Care Programme in Surrey and Sussex is a further example of an SHA-wide approach. This programme was set up by the 15 PCTs in Surrey and Sussex, rather than the SHA, in partnership with people with long-term conditions, social care, acute trusts, and the voluntary sector. It draws on the Wagner model and the Kaiser triangle, and, as its name suggests, sets out a programme of action across the whole system of care.

The NHS Health and Social Care Model is being used by the Thames Valley SHA and Trent SHA, the latter also drawing on the Kaiser triangle and the Evercare approach to case management.

In other SHA areas, a wide variety of models have been adopted, based on the decisions of PCTs. The responses suggest that in many cases SHAs have facilitated collaboration between PCTs to exchange ideas and experience. Two examples are North West London, which has initiated a long-term conditions collaborative, and West Yorkshire which has encouraged PCTs to work with each other and to network with PCTs in other SHA areas in developing their approach to long-term conditions.

In other cases, it would appear from the responses that most SHAs have been less directly involved and have taken the view that PCTs are in the driving seat on this policy.

APPROACHES IN USE IN THE NHS

As might be expected from the location of leadership responsibility with PCTs, a wide variety of approaches have been adopted to support implementation of the NHS and Social Care Model. Those mentioned in the responses to the survey were:

- Wagner's Chronic Care Model (broad conceptual model),
- Kaiser's triangle (service delivery model),
- Evercare (service delivery model),
- Unique Care / Castelfields (service delivery model),
- NPDT collaborative eg on COPD (service delivery model),
- Expert Patient Programme (service delivery model),
- Pursuing Perfection (service delivery model),
- PARR tool developed by King's Fund (service delivery model).

The varied quantity and quality of information supplied in each response and the diverse sources of this information (PCT or SHA) makes it difficult to be more precise about the models that have been adopted most frequently.

In some cases, models have been adapted by SHAs and PCTs. For example, the South Yorkshire model described above; the addition of end of life care to the Kaiser triangle in Birmingham and Black Country SHA; and adding informatics and data analysis in various SHAs.

There appears to have been a particular emphasis to date on service delivery models that focus on case management and the use of community matrons, such as Evercare and Unique Care / Castlefields. This reflects the priority attached to case management and community matrons by the Department of Health. An example is Essex SHA whose approach is informed by the Kaiser triangle but whose strategic framework document focuses on case management and sets out the principles to be used to develop case management.

Similarly, most of the responses from PCTs (for example, from Kent and Medway) emphasised the work they are doing to appoint community matrons and strengthen services for people with long-term conditions at level three of the Kaiser triangle.

Indeed, most SHAs and PCTs that provided information about the components of the model they were using typically referred to the three levels of the Kaiser triangle and rarely referred to other elements.

REASONS FOR CHOOSING DIFFERENT MODELS

We asked SHAs why they had selected specific approaches. Responses to this question were less detailed than to the request for information about which frameworks they were drawing on.

In a small number of cases, it was reported that models had been chosen after a review of the evidence about different approaches (Surrey and Sussex, Essex, Dorset and Somerset, South Yorkshire, and North East London).

Three responses referred to the importance of international links with Kaiser (Leicestershire, Northamptonshire and Rutland, and Surrey and Sussex) and United Health Europe (Trent).

In other cases, the reasons given focused on individual preferences, including:

- a desire to continue with approaches already in place (North West London and South Hams and West Devon PCT),
- a preference for a generic rather than a disease-specific model (Birmingham and Black Country),
- a desire to adopt a model that fitted local circumstances and was not overly medically orientated (North and East Yorkshire and Northern Lincolnshire),
- and Department of Health guidance (Thames Valley).

A number of responses suggested that they had chosen a model because it was most likely to contribute to targets such as bed day reductions.

The remaining responses did not provide sufficient information to identify the reasons for choosing a particular approach.

IMPACTS

We asked SHAs whether their approaches were having any impact. The most common response to this question was that 'it is too early to say.'

Beyond this, a number of responses referred to 'anecdotal evidence' that the approaches adopted were beginning to have an impact, for instance in slowing and reducing emergency bed day use. Some of these responses included data illustrating changes following the introduction of case management and similar interventions. Others indicated that impact was being evaluated by PCTs without providing further information.

A number of the responses gave examples of more detailed frameworks for evaluating the impact of models. Some of these frameworks outlined ambitious attempts to evaluate the impact of the long-term conditions policy along a number of dimensions. An example is the approach taken in Surrey and Sussex which is tracking patient experience, processes, staff views, and resource use. The table overleaf lists the key targets and measurement tools being used in Surrey and Sussex. Baseline information has been collected in 2005 and this will be followed up in late 2007 / early 2008.

The management reports and policy papers that accompanied the responses to the survey included many examples of local audits and stocktakes undertaken to track progress to date. An example is the approach being taken in Shropshire and Staffordshire where the SHA is undertaking a stocktake with PCTs to assess progress in six areas:

- identification of people at levels 3, 2 and 1,
- personalised care plans for complex patients,
- implementation of community matrons,
- measures for achieving the targets and local priorities including financial balance,
- overall continued strategic planning and leadership,
- and effective communication.

An example of a local audit is the evaluation of the Eldercare Project in Cornwall (EPIC) undertaken by three PCTs in Cornwall. This evaluation now forms the basis of the approach to chronic disease management in Cornwall.

Another example is the East Riding Case Management Pilots Evaluation Report that found a 56% reduction in admissions and a 73% reduction in emergency bed days in the pilot phase.

A few responses indicated an intention to establish comprehensive evaluations in due course. For example, Birmingham and Black Country and Trent are working with United Health Europe in developing its approach.

Evaluation framework being used in Surrey and Sussex¹⁴⁹

Outcomes	Indicators / Targets	Measurement	Outcomes	Indicators/ Targets	Measurement
People feel more informed about their condition and care	75% of people with long-term conditions feel informed about their condition and care	Surrey and Sussex wide survey (2005 and 2008)	Increased shared vision of service provision	80% of NHS staff are aware of the chronic care model	MORI NHS staff survey
	100% of PCT areas develop new resources or delivery methods	Annual PCT self-assessment audit		10% of staff working with people with long-term conditions take part in joint learning each year	Annual PCT self-assessment audit
Increased sense of control	25% of people with long-term conditions take part in self-management education programme	Surrey and Sussex wide survey (2005 and 2008); EPP data	Increased job satisfaction	33% of NHS LTC staff say they are more satisfied with their role	MORI NHS staff survey,
	Expert Patient Programme or equivalent available in 80% of areas	EPP data Annual PCT self-assessment audit		33% of NHS staff working in chronic care feel more able to make a difference	MORI NHS staff survey
	50% of people with long-term conditions say they feel in control of and involved in planning care	Surrey and Sussex wide survey (2005 and 2008)		50% of staff working with people with long-term conditions feel there is less duplication of effort	MORI NHS staff survey
Improved experience of care	50% of people with long-term conditions perceive improved quality, accessibility, and consistency of care	Surrey and Sussex wide survey (2005 and 2008)	Improved perception of service systems	75% of staff working with people with long-term conditions feel services are more co-ordinated	MORI NHS staff survey
	5% reduction in complaints from people with chronic conditions	PALs and PCT quarterly Board reports		75% of staff think information is more likely to be shared between staff and between organisations	MORI NHS staff survey
	90% of those eligible are assigned to a case manager	Routinely collected data		75% of staff trust that colleagues they refer patients to will treat patients appropriately	MORI NHS staff survey
	90% of people receive annual medical reviews	Routinely collected data			
Improved quality of life	50% of people have improved quality of life	Patient survey (2005 and 2008)			
Improved clinical indicators	10% reduction in emergency admissions for each condition	Routinely collected data	Better co-ordinated care	100% of PCT areas implement single assessment process	Annual PCT self audit
	Absolute increase of 10% in proportion of people with specified QoF markers	Routinely collected data		80% of PCT areas adopt standardised risk stratification / triggers	Annual PCT self-assessment audit
	Absolute increase of 10% in people with heart failure prescribed ACE inhibitors / beta blockers	Routinely collected data		100% of PCT areas adopt case management for those at high risk	Annual PCT self-assessment audit
	10% increase in people with stroke who are prescribed aspirin or clopidogrel	Routinely collected data		75% of patients and 75% of staff feel care is well co-ordinated	Patient and staff surveys
	Improved 'cost effectiveness' for prescribing	Routinely collected data		75% feel there are partnerships between patients and staff	Patient and staff surveys
Reduced emergency admissions	10% reduction in emergency admissions	Routinely collected data	Improved referral systems	33% of PCT areas have self referral policies to specialists	Annual PCT self audit
Reduced emergency hospital days	Adjusted PSA target: 1.8% by March 2006; 6.9% by March 2007; 12% by March 2008	Routinely collected data		25% of PCT areas reduce referral / entry forms for patients or have drop-in services	Annual PCT self-assessment audit
Redeployment of resources towards community care and health promotion	5% shift in finances used for chronic conditions towards self-management and health promotion	Annual PCT self-assessment audit	Improved shared info systems	80% of PCT areas use shared data management tools / registries / definitions / triggers	Annual PCT self-assessment audit
	5% increase in resources (finances and staff) available for community and social care	Annual PCT self-assessment audit	Partnership with local government , community, and voluntary sector	50% of PCT areas proactively working with voluntary / non health sector	Annual PCT self-assessment audit
	Case management introduced at same or lower overall cost of care for frequently admitted patients	Annual PCT self-assessment audit		80% of PCT areas moving towards integrated health and social care system with joint targets	Annual PCT self-assessment audit

People with long-term conditions

Resources

Professionals

Processes

SUMMARY OF SURVEY RESPONSES

Feedback from SHAs suggests:

- SHAs have adopted different styles to developing their approach to long-term conditions ranging from promoting SHA-wide models, seeing PCTs as having the lead responsibility, and supporting PCTs through collaborative and networking activities.
- A wide range of approaches have been adopted to support implementation of the NHS and Social Care Model, including broad frameworks such as Wagner's Chronic Care Model, and service delivery approaches such as the Kaiser triangle and EverCare.
- There has been a particular interest in developing case management drawing on EverCare, Unique Care / Castlefields and similar approaches.
- The reasons cited for choosing different approaches include the evidence base, international experience, Department of Health guidance, continuing existing approaches, a preference for generic models, and wanting to use models that will meet targets.
- Good quality evidence on the impact of the approaches is lacking, with most respondents reporting that it is too early to present rigorous evidence. Anecdotal evidence indicates that case management may be reducing emergency bed day use and a number of SHA areas are planning to evaluate their programmes more systematically in the future. At least one SHA area has set up an extensive evaluation programme.

Summary of responses from each SHA area

PCT area	Response	Model	Impact
<i>Shropshire & Staffordshire</i>	Response from SHA	No SHA wide model. PCTs have developed own models focused on case management	Impact reviewed in SHA stocktake in January 2005 and planned for 2006
<i>North West London</i>	Response from SHA	No SHA wide model. PCTs have developed own models focused on case management	Evaluations being undertaken by PCTs
<i>North East London</i>	Response from SHA	Variety of models dominated by Wagner approach with examples of Evercare and Unique Care	Evaluations being planned
<i>South East London</i>	Response from SHA	No SHA wide model. PCTs have developed own models – some disease specific and others generic, including Evercare, Pursuing Perfection, COPD collaborative, Expert Patient and King's Fund PARR	Each project has own evaluation criteria. Too little comparable data and too early to say if objectives achieved
<i>Thames Valley</i>	Response from SHA	The NHS Health and Social Care Model has been adopted across the SHA	SHA has developed guidance for PCTs on evaluation of matrons
<i>Essex</i>	Response from SHA	SHA developed framework for case management for use by PCTs and has encouraged application of King's Fund PARR tool	Anecdotal evidence suggests some effect on emergency bed day use although too early to attribute
<i>Surrey and Sussex</i>	SHA / PCT Alliance	The Transforming Chronic Care Programme involves all 15 PCTs and has adapted the Wagner and Kaiser models across the SHA area	A detailed evaluation is underway to assess impact on a number of dimensions
<i>Kent and Medway</i>	Responses from PCTs	Medway PCT has adopted the Kaiser model. Canterbury and Coastal PCT has adopted The NHS Health and Social Care Model and has appointed community matrons as part of the Empowering Patients Independence care programme. East Kent Coastal PCT has focused on case management drawing on Evercare and Castlefields	It is too early to assess impact. East Kent Coastal PCT is developing a data collection tool to measure service outcomes
<i>South West Peninsula</i>	Responses from PCTs	Mid Devon PCT is focusing on case management using Evercare, chosen because of potential to reduce non-elective admissions. Exeter PCT has adapted the Kaiser model and a whole system approach. South Hams and West Devon PCT has adapted an existing generic model (called Closer to Home). The three Cornwall PCTs have used a number of models including Evercare and Kaiser	Individual PCTs are conducting their own assessments. It is too early to assess impact. In Cornwall, PCTs have undertaken an evaluation of the Eldercare Project which provides case management for people aged over 75. This suggests progress in reducing emergency admissions.
<i>Dorset and Somerset</i>	Response from SHA	The Kaiser triangle has been adopted across the SHA area	It is too early to say if the model is making a difference, but there are some early indications of emergency bed day savings
<i>Avon, Gloucestershire and Wiltshire</i>	Responses from PCTs	Gloucester PCT has used the Kaiser triangle and drawn on Castlefields and Evercare approaches. North Somerset PCT is hoping to draw on Unique Care in developing its approach, and is involved in the NPDT collaboratives in COPD and diabetes	It is too early to assess impact
<i>Hampshire and Isle of Wight</i>	Response from SHA	SHA has a strategic facilitation programme but PCTs provide the clinical leadership for the vision, strategy and implementation. PCTs are taking different approaches	It is too early to assess impact
<i>West Midlands South</i>	Responses from PCTs	South Warwickshire PCT has adapted the Kaiser model. Herefordshire PCT has used the Kaiser model and also drawn on the Wagner model and its approach will be evaluated	It is too early to assess impact
<i>Birmingham and Black Country</i>	Response from SHA	PCTs have developed their own models and these have been linked back to the Kaiser model. United Healthcare Europe is involved in an informatics programme to provide risk profiling	The approach will be evaluated using data from the informatics programme and other sources
<i>Northumberland, Tyne and Wear</i>	Response from SHA	No SHA wide model. PCTs have developed their own models, including the Wagner approach and Unique Care	SHA is promoting a benefits realisation framework. It is too early to assess impacts
<i>Leicestershire, Northamptonshire and Rutland</i>	Response from SHA	The Kaiser model has been adopted across the SHA area	An evaluation framework is being developed to assess impact
<i>North and East Yorkshire and Nth Lincolnshire</i>	Response from SHA	No SHA wide model. PCTs have developed their own models focused on case management and influenced by Unique Care	The approaches adopted are starting to slow the increase in admissions and bed days
<i>South Yorkshire</i>	Response from SHA	The Wagner and Kaiser models have been adapted into an SHA wide approach	Evidence on impact is sketchy
<i>West Yorkshire</i>	Response from SHA	PCTs have developed their own models. These models have drawn on Unique Care / Castlefields, Evercare, Kaiser, and Expert Patient Programme	
<i>Trent</i>	Response from SHA	The NHS and Social Care Model has been adopted with case management supported by United Healthcare Europe / Evercare and Kaiser triangle	It is too early to evaluate the model but there is some anecdotal evidence

SECTION 4: SUMMARY

What models of chronic care have been used internationally?

This rapid review suggests that the Chronic Care Model and the related Innovative Care for Chronic Conditions Model are the most common frameworks for conceptualising effective components of care for people with long-term conditions. The Kaiser pyramid of care appears to be used throughout the developed world to conceptualise service delivery. While a number of other approaches guide service delivery, these tend not to be conceptualised as formal models, nor are their components clearly articulated.

Summary of named models

Model	Origin	Key components	Evidence of impact
<i>Broad frameworks</i>			
NHS and Social Care	UK	<ul style="list-style-type: none"> Risk assessment Targeting frequent users Case management by matrons Multidisciplinary teams Self management 	We identified no evidence about the effectiveness of this model, although it is newly implemented so it is too early to gauge effects
Chronic Care Model and revised 'Care Model' and 'Expanded Chronic Care Model'	US	<ul style="list-style-type: none"> Community resources Healthcare system Self-management Decision support Delivery system redesign Clinical information systems 	We identified evidence that components of the model can improve quality of care and resource use. We identified no comparative evidence about whether this model is better than other frameworks
Innovative Care for Chronic Conditions	WHO	<ul style="list-style-type: none"> Micro level (individual, family, and health staff) Meso level (community and health care organisations) Macro level (policy) 	We identified no evidence about the effectiveness of this model
Public Health Model	US	<ul style="list-style-type: none"> Population-wide policies Community activities Health services 	We identified no evidence about the effectiveness of this model
Continuity of Care Model	US	<ul style="list-style-type: none"> Tracks intervention needs from general population through to those needing palliative care 	We identified no evidence about the effectiveness of this model
<i>Service delivery approaches</i>			
Kaiser Model	US	<ul style="list-style-type: none"> Care provided care based on risk assessment Case management for those with complex needs Care management for 20-30% Supported self care for most 	Evidence from the US suggests that this model can provide more integrated care and reduce hospital admissions
Evercare and Pfizer models	US	<ul style="list-style-type: none"> Focuses on identifying those at highest risk for hospitalisation and providing nurse led case management (Evercare) or telephone support (Pfizer) 	There is evidence that the Evercare and Pfizer models may reduce healthcare costs in the US. A UK evaluation of Evercare found increased identification of unmet needs
Strengths Model	US	<ul style="list-style-type: none"> Self empowerment Identifying people's capacities 	We identified no evidence about this model
Veteran's Affairs	US	<ul style="list-style-type: none"> Similar to Chronic Care Model, but applied to particular population segment 	We identified no additional evidence about implementing this model in the US Veteran's Affairs system, other than that focussed on the generic Chronic Care Model
Guided Care	US	<ul style="list-style-type: none"> Nurse-led care 	No evidence about this model
PACE	US	<ul style="list-style-type: none"> Integrated care for the elderly Targeting day centre users Single access point 	There is limited evidence about this model, although it may reduce hospital admissions and increase nursing home use

What evidence is there about the impacts of these models?

There is limited high quality evidence about the impact of any model.

Although components of the Chronic Care Model have been studied extensively and a detailed evaluation has been undertaken in the US, it is still unclear whether this model is any more effective than others. This is largely because other models are not well conceptualised or described. However, there is also limited information about whether *all components* of the Chronic Care Model are necessary or effective.

There is evidence that improvement programmes which aim to implement the Chronic Care Model can have a sustainable impact on quality of care and some clinical and resource outcomes. The relative merits of each component of the model, and the extent to which these are implemented effectively by healthcare organisations, is still under review.

There is almost no evaluative information about any other broad chronic care framework.

Evaluations of specific models of service delivery, such as the Kaiser and Evercare approaches, are available. These suggest that specific service delivery models may have some impacts on quality of care and healthcare resource use, however most high quality evidence is drawn from the US health system.

What approaches have been adopted by Strategic Health Authorities?

SHAs have adopted different styles to developing their approach to long-term conditions, with some taking the lead or facilitating PCT collaborations and others leaving policy in the hands of individual PCTs.

A wide range of approaches have been adopted in SHAs and PCTs, including broad frameworks such as Wagner's Chronic Care Model, and service delivery approaches such as the Kaiser triangle and EverCare. Many of the SHAs are focussing on service delivery models and case management, rather than a broader approach taking into account multifaceted components.

The majority of SHAs had based their decisions about which approach to adopt on pragmatic or experiential factors rather than research evidence.

As yet, it appears too early to say whether any of the models implemented are having an impact on chronic care.

REFERENCES

- 1 *Chronic disease management: A compendium of information*. London: Department of Health, 2004.
- 2 *Improving Chronic Disease Management*. London: Department of Health, 2004.
- 3 *Supporting People with Long Term Conditions. An NHS and Social Care Model to Support Local Innovation and Integration*. London: The Stationery Office, 2005.
- 4 *Supporting People with Long Term Conditions. An NHS and Social Care Model to Support Local Innovation and Integration*. London: The Stationery Office, 2005.
- 5 Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the chronic care model, Part 2. *JAMA* 2002; 288(15): 1909-14.
- 6 Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? *Eff Clin Pract* 1998; 1: 2-4.
- 7 Care of depression in older patients. proceedings of a symposium. *Int Clin Psychopharmacol* 1998; 13(Suppl 5): S1-S9.
- 8 Sperl-Hillen J, O'Connor PJ, Carlson RR et al. Improving diabetes care in a large health care system: an enhanced primary care approach. *Jt Comm J Qual Improv* 2000; 26(11), 615-22.
- 9 Fulton TR, Penney BC, Taft A. Exploring a chronic care model in a regional healthcare context. *Healthc Manage Forum* 2001; 14(2): 6-24.
- 10 Chin MH, Cook S, Drum ML et al. Improving diabetes care in midwest community health centers with the health disparities collaborative. *Diabetes Care* 2004; 27(1): 2-8.
- 11 Siminerio LM, Piatt G, Zgibor JC. Implementing the chronic care model for improvements in diabetes care and education in a rural primary care practice. *Diabetes Educ* 2005; 31(2): 225-34.
- 12 Stroebe RJ, Gloor B, Freytag S et al. Adapting the chronic care model to treat chronic illness at a free medical clinic. *J Health Care Poor Underserved* 2005; 16(2): 286-96.
- 13 Reproduced with permission from the American College of Physicians (ACP Online).
- 14 Tsai AC, Morton SC, Mangione CM, Keeler EB. A meta-analysis of interventions to improve care for chronic illnesses. *Am J Manag Care* 2005; 11(8): 478-88.
- 15 <http://www.improvingchroniccare.org/change/model/expandedmodel.htm>
- 16 Barr VJ, Robinson S, Marin-Link B et al. The expanded chronic care model: an integration of concepts and strategies from population health promotion and the chronic care model. *Hosp Q* 2003; 7(1): 73-82.
- 17 *A Framework for a Provincial Chronic Disease Prevention Initiative*. British Columbia: Population Health and Wellness, Ministry of Health Planning; 2003
- 18 *Curing the System: Stories of Change in Chronic Illness Care*. US: ACT, 2002.
- 19 Grol R, Grimshaw JM. Evidence-based implementation of evidence-based medicine. *Jt Comm J Qual Improv* 1999; 25(10): 503-13.
- 20 Cretin S, Shortell SM, Keeler EB. An evaluation of collaborative interventions to improve chronic illness care: framework and study design. *Evaluation Review* 2004; 28(1): 28-51.
- 21 Von Korff MJ, Gruman J, Schaefer SJ et al. Collaborative management of chronic illness. *Ann Int Med* 1997; 127(12): 1097-102.
- 22 Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. *Milbank Quarterly* 1996; 74(4): 511-44.
- 23 Daniel DM, Norman J, Davis C et al. Case studies from two collaboratives on diabetes in Washington State. *Jt Comm J Qual Saf* 2004; 30(2): 103-108.
- 24 Glasgow RE, Funnell MM, Bonomi AE et al. Self-management aspects of the improving chronic illness care breakthrough series: implementation with diabetes and heart failure teams. *Ann Behav Med* 2002; 24(2): 80-7.
- 25 Wagner EH, Glasgow RE, Davis C et al. Quality improvement in chronic illness care: a collaborative approach. *Jt Comm J Qual Improv* 2001; 27(2): 63-80.
- 26 Wang A, Wolf M, Carlyle R et al. The North Carolina experience with the diabetes health disparities collaboratives. *Jt Comm J Qual Saf* 2004; 30(7): 396-404.
- 27 Nuovo J, Balsbaugh T, Barton S et al. Development of a diabetes care management curriculum in a family practice residency program. *Dis Manag* 2004; 7(4): 314-24.
- 28 *Curing the System: Stories of Change in Chronic Illness Care*. US: ACT, 2002.
- 29 Shortell SM, Marsteller JA, Lin M et al. The role of perceived team effectiveness in improving chronic illness care. *Med Care* 2004; 42(11): 1040-8.
- 30 Wu SY, Pearson ML, Keeler EB. Sustainability and spread of chronic illness care improvement. http://www.rand.org/health/projects/ice/improve_illness.html
- 31 Pearson ML, Wu S, Schaefer J et al. Assessing the implementation of the chronic care model in quality improvement collaboratives. *Health Serv Res* 2005; 40(4): 978-96.
- 32 Mangione-Smith R, Schonlau M, Chan KS et al. Measuring the effectiveness of a collaborative for quality improvement in pediatric asthma care: does implementing the chronic care model improve processes and outcomes of care? *Ambul Pediatr* 2005; 5(2): 75-82.
- 33 Schonlau M, Mangione-Smith R, Chan KS et al. Evaluation of a quality improvement collaborative in asthma care: does it improve processes and outcomes of care? *Ann Fam Med* 2005; 3(3): 200-8.
- 34 Schonlau M, Mangione-Smith R, Rosen M et al. An evaluation of an adult asthma bts collaborative: process of care and outcomes. <http://www.rand.org/health/projects/ice/MSasthmaABS.html>
- 35 Vargas RB, Mangione CM, Keesey J et al. Do collaborative quality improvement programs reduce cardiovascular risk for persons with diabetes? <http://www.rand.org/health/projects/ice/vargas.html>
- 36 Baker DW, Asch S, Brown J et al. Improvements in communication, education, and self-management through implementation of the chronic care model for patients with heart failure. http://www.rand.org/health/projects/ice/heart_care.html
- 37 Meredith LS, Mendel P, Pearson M. Success of implementation and maintenance of quality improvement for depression. http://www.rand.org/health/projects/ice/improve_depression.html
- 38 Pearson ML, Wu SY, Schaefer J et al. Assessing the implementation of the chronic care model in quality improvement collaboratives. *Health Services Research* 2005; 40(4): 978-96.
- 39 Pearson ML, Wu SY, Shortell S et al. Chronic care model (CCM) implementation emphases. <http://www.rand.org/health/projects/ice/ccm.html>
- 40 Tsai AC, Morton SC, Mangione CM, Keeler EB. A meta-analysis of interventions to improve care for chronic illnesses. *Am J Manag Care* 2005; 11(8): 478-88.
- 41 Bodenheimer T. Interventions to improve chronic illness care: evaluating their effectiveness. *Dis Manag* 2003; 6(2): 63-71.

- 42 Wagner EH, Austin BT, Davis C et al. Improving chronic illness care: translating evidence into action. *Health Affairs* 2001; 20(6): 64-78.
- 43 McAlister FA, Lawson FM, Teo KK, Armstrong PW. Randomised trials of secondary prevention programmes in coronary heart disease: systematic review. *BMJ* 2001; 323(7319): 957-62.
- 44 Endicott L, Corsello P, Prinzi M et al. Operating a sustainable disease management program for chronic obstructive pulmonary disease. *Lippincotts Case Manag* 2003; 8(6): 252-62.
- 45 Neumeier-Gromen A, Lampert T, Stark K, Kallischnigg G. Disease management programs for depression: a systematic review and meta-analysis of randomized controlled trials. *Med Care* 2004; 42(12): 1211-21.
- 46 Chin MH, Cook S, Drum ML et al. Improving diabetes care in midwest community health centers with the health disparities collaborative. *Diabetes Care* 2004; 27(1): 2-8.
- 47 Ouwers M, Wollersheim H, Hermens R et al. Integrated care programmes for chronically ill patients: a review of systematic reviews. *Int J Qual Health Care* 2005 17(2):141-6.
- 48 Philbin EF. Comprehensive multidisciplinary programs for the management of patients with congestive heart failure. *J General Internal Medicine* 1999; 14(2): 130-5.
- 49 Badamgarav E, Croft JD Jr, Hohlbauch A, et al. Effects of disease management programs on functional status of patients with rheumatoid arthritis. *Arthritis Rheum* 2003; 49(3): 377-87.
- 50 <http://www.rand.org/health/projects/ice/>
- 51 Sperl-Hillen JM, Solberg LI, Hroschowski MC, et al. Do all components of the chronic care model contribute equally to quality improvement? *Jt Comm J Qual Saf* 2004; 30(6): 303-9.
- 52 Lin MK, Marsteller JA, Shortell SM et al. Motivation to change chronic illness care: results from a national evaluation of quality improvement collaboratives. *Health Care Manage Rev* 2005; 30(2): 139-56.
- 53 Wagner E. Preventing decline in function: evidence from randomized trials around the world. *West J Med* 1997; 167(4): 295-8.
- 54 Gonseth J, Guallar-Castillon P, Banegas JR, Rodriguez-Artalejo F. The effectiveness of disease management programmes in reducing hospital re-admission in older patients with heart failure: a systematic review and meta-analysis of published reports. *Eur Heart J* 2004; 25(18): 1570-95.
- 55 Rich MW. Heart failure disease management: a critical review. *J Card Fail* 1999; 5: 64-75.
- 56 Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the Chronic Care Model, Part 2. *JAMA* 2002; 288(15): 1909-14.
- 57 Wellingham J, Tracey J, Rea H, Gribben B. The development and implementation of the Chronic Care Management Programme in Counties Manukau. *NZ Med J* 2003; 116(1169): 327.
- 58 Demers D, Clark N, Tolmann G et al. Computer simulated cost effectiveness of care management strategies on reduction of long-term sequelae in patients with non-insulin dependent diabetes mellitus. *Quality Management in Health Care* 1997; 6(1): 1-13.
- 59 Philbin EF, Rocco TA, Lindenmuth NW, et al. The results of a randomized trial of a quality improvement intervention in the care of patients with heart failure. *Am J Med* 2000; 109(6): 443-9.
- 60 *Are disease management programmes (DMPs) effective in improving quality of care for people with chronic conditions?* WHO Regional Office for Europe's Health Evidence Network (HEN), 2003.
- 61 McDonald HP, Garg AX, Haynes RB. Interventions to enhance patient adherence to medication prescriptions: scientific review. *JAMA* 2002; 288(22): 2868-79.
- 62 Friedman NM, Gleeson JM, Kent MJ. Management of diabetes mellitus in the Lovelace Health Systems' EPISODES OF CARE program. *Eff Clin Pract* 1998; 1(1): 5-11.
- 63 Sperl-Hillen J, O'Connor PJ, Carlson RR et al. Improving diabetes care in a large health care system: an enhanced primary care approach. *Jt Comm J Qual Improv* 2000; 26(11): 615-22.
- 64 Walsh MN, Simpson RJ Jr, Wan GJ et al. Do disease management programs for patients with coronary heart disease make a difference? Experiences of nine practices. *Am J Manag Care* 2002; 8(11): 937-46.
- 65 Feifer C, Ornstein SM, Nietert PJ, Jenkins RG. System supports for chronic illness care and their relationship to clinical outcomes. *Top Health Inf Manage* 2001; 22(2): 65-72.
- 66 Epping-Jordan JE, Pruitt SD, Bengoa R, Wagner EH. Improving the quality of health care for chronic conditions. *Qual Saf Health Care* 2004; 13(4): 299-305.
- 67 *Innovative Care for Chronic Conditions: Building Blocks for Action*. Geneva: World Health Organisation, 2002.
- 68 http://www.who.int/chronic_conditions/evidence/en/
- 69 Robles SC. A public health framework for chronic disease prevention and control. *Food Nutr Bull* 2004; 25(2): 194-9.
- 70 Centers for Disease Control and Prevention. *Promising Practices in Chronic Disease Prevention and Control: A Public Health Framework for Action*. Atlanta: Department of Health and Human Services, 2003.
- 71 Sunol R, Carbonell JM, Nualart L et al. Towards health care integration: The proposal of an evidence-and management system-based model. *Med Clin* 1999; 112 suppl 1:97-105.
- 72 McGonigle JJ, Krouk M, Hindmarsh D, Campano-Small C. Understanding partial hospitalization through a continuity-of-care model. *Int J Partial Hosp* 1992; 8(2): 135-40.
- 73 Klingbeil GE, Fiedler IG. Continuity of care. A teaching model. *Am J Phys Med Rehabil* 1988; 67(2): 77-81.
- 74 Homer J et al. *The CDC's Diabetes Systems Modeling Project: Developing a New Tool for Chronic Disease Prevention and Control*. 22nd International Conference of the System Dynamics Society. July 25-29, 2004. Oxford, England.
- 75 Walker B, Haslett T. System dynamics and action research in aged care. *Aust Health Rev* 2001; 24(1): 183-91.
- 76 Wallace PJ. Physician involvement in disease management as part of the CCM. *Health Care Financ Rev* 2005; 27(1): 19-31.
- 77 Feachem RG, Sekhri NK, White KL. Getting more for their dollar: a comparison of the NHS with California's Kaiser Permanente. *BMJ* 2002; 324(7330): 135-41.
- 78 PEC Paper 4. United Healthcare, NHS Modernisation Agency, 2004
- 79 <http://www.natpact.nhs.uk/cms/4.php>
- 79 Mollica RL, Gillespie J. *Care Co-ordination for People with Chronic Conditions*. Baltimore: Partnership for Solutions, 2003.
- 80 Mollica RL, Gillespie J. *Coordinating Care for the Chronically Ill How Do We Get There From Here?* Baltimore: Partnership for Solutions, 2003.
- 81 Mechanic R. *Will care management improve the value of US healthcare?* Background paper for the 11th Annual Princeton Conference, May 20 - 21, 2004.

- 82 Singh D. *Transforming Chronic Care: Evidence about improving care for people with long-term conditions*. Birmingham: University of Birmingham and Surrey and Sussex PCT Alliance, 2005.
- 83 Kane RL et al. The effect of Evercare on hospital use. *J Am Geriatr Soc* 2003; 51: 1427-34.
- 84 Smith R. Improving the management of chronic disease. *BMJ* 2003; 327: 12.
- 85 <http://libraries.nelh.nhs.uk/healthManagement/viewResource.asp?categoryID=4031&dg=62&uri=http%3A//libraries.nelh.nhs.uk/common/resources/?id%3D59865>
- 86 *Implementing the Evercare Programme*. Interim Report, 2004.
- 87 Boaden R, Dusheiko M, Gravelle H et al. *Evercare Evaluation Interim Report: Implications For Supporting People With Long-Term Conditions*. Manchester: The National Primary Care Research and Development Centre, 2005.
- 88 Boaden R, Dusheiko M, Gravelle H et al. *Evercare Evaluation Interim Report: Implications For Supporting People With Long-Term Conditions*. Manchester: The National Primary Care Research and Development Centre, 2005.
- 89 <http://libraries.nelh.nhs.uk/healthManagement/viewResource.asp?categoryID=4031&dg=62&uri=http%3A//libraries.nelh.nhs.uk/common/resources/?id%3D57035>
- 90 <http://libraries.nelh.nhs.uk/healthManagement/viewResource.asp?categoryID=4031&dg=62&uri=http%3A//libraries.nelh.nhs.uk/common/resources/?id%3D59895>
- 91 Sobel D. *Patients As Partners. Improving Health And Cost Outcomes With Self Care And Chronic Disease Self Management*. NatPaCT conference presentation, 4 November 2003.
- 92 Ham C. *Learning from Kaiser Permanente: a progress report*. Unpublished paper. Department of Health, 2003.
- 93 Fast B, Chapin R. The strengths model in long-term care: linking cost containment and consumer empowerment. *J Case Manag* 1996; 5(2): 51-7.
- 94 Feldman HM, Ploof D, Cohen WI. Physician-family partnerships: the adaptive practice model. *J Dev Behav Pediatr* 1999; 20(2):111-6.
- 95 Boulton C. Guided Care: Integrating High Tech and High Touch. Unpublished abstract, 2005.
- 96 'Guided care' model offers a new approach for costly, complex cases. *Dis Manag Advis* 2005; 11(8): 90-1.
- 97 Boulton C. Guided Care: Improving the Quality of Life for Older Americans with Complex Health Care Needs. Unpublished abstract, 2005.
- 98 Mui AC. The Program of All-Inclusive Care for the Elderly (PACE): an innovative long-term care model in the United States. *J Aging Soc Policy* 2001; 13(2-3): 53-67.
- 99 Eng C, Pedulla J, Eleazer GP et al. Program of All-inclusive Care for the Elderly (PACE): an innovative model of integrated geriatric care and financing. *J Am Geriatr Soc* 1997; 45(2): 223-32.
- 100 Lee W, Eng C, Fox N, Etienne M. PACE: a model for integrated care of frail older patients. Program of All-inclusive Care for the Elderly. *Geriatrics* 1998; 53(6): 62-6.
- 101 Greenwood R. The PACE model. *Issue Brief Cent Medicare Educ* 2001; 2(10): 1-8.
- 102 Rich ML. The PACE model: description and impressions of a capitated model of long-term care for the elderly. *Care Manag J* 1999; 1(1): 62-70.
- 103 Branch LG, Coulam RF, Zimmerman YA. The PACE evaluation: initial findings. *Gerontologist* 1995; 35(3): 349-59.
- 104 Gross DL, Temkin-Greener H, Kunitz S, Mukamel DB. The growing pains of integrated health care for the elderly: lessons from the expansion of PACE. *Milbank Q* 2004; 82(2): 257-82.
- 105 Nadash P. Two models of managed long-term care: comparing PACE with a Medicaid-only plan. *Gerontologist* 2004; 44(5): 644-54.
- 106 Mechanic R. *Will care management improve the value of US healthcare?* Background paper for the 11th Annual Princeton Conference, May 20 - 21, 2004.
- 107 Partnership for Care: Scotland's Health White Paper. <http://www.scotland.gov.uk/Publications/2003/02/16476/18736>
- 108 Partnership for Care: Scotland's Health White Paper. <http://www.scotland.gov.uk/Publications/2003/02/16476/18736>
- 109 *Designed for Life*. Welsh Assembly Government, 2005.
- 110 *Overview of the Evidence on Effective Service Models in Chronic Disease Management*. Welsh Assembly Government, 2005.
- 111 Stuart M, Weinrich M. Integrated health system for chronic disease management: lessons learned from France. *Chest* 2004; 125: 695-703.
- 112 Scalvini S, Volterrani M, Giordano A et al. Boario Home Care Project: an Italian telemedicine experience. *Monaldi Arch Chest Dis* 2003; 60: 254-7.
- 113 de Toledo P, Jimenez S, Del Pozo F. A telemedicine system to support a new model for care of chronically ill patients. *J Telemed Telecare* 2002; 8 Suppl 2: 17-9.
- 114 Stuart M, Weinrich M. Integrated health system for chronic disease management. Lessons learned from France. *Chest* 2004; 125: 695-703.
- 115 Frohlich A, Jorgensen J. Improving care in patients with chronic conditions. <http://www.integratedcarenetwork.org/publish/articles/000045/article.htm>
- 116 Stuart M, Weinrich M. Home and community based long-term care: lessons from Denmark. *Gerontologist* 2001; 41: 474-80.
- 117 Bosch X. Spain's home healthcare programme goes nationwide. *BMJ* 2000; 320: 535.
- 118 Frohlich A, Jorgensen J. Improving care in patients with chronic conditions. <http://www.integratedcarenetwork.org/publish/articles/000045/article.htm>
- 119 Ricciardi G. The Italian model for long-term care. *Health Care Manag* 1997; 3(1): 167-76.
- 120 Busse R. Disease management programs in Germany's statutory health insurance system. *Health Affairs* 2004; 23: 56-67.
- 121 Guterman S. U.S. and German Case Studies in Chronic Care Management: An Overview. *Health Care Financ Rev* 2005; 27(1): 1-8.
- 122 Temmink D, Hutten JB, Francke AL et al. Rheumatology out-patient nurse clinics: a valuable addition? *Arthritis Rheum* 2001; 45: 280-6.
- 123 Guterman S. U.S. and German Case Studies in Chronic Care Management: An Overview. *Health Care Financ Rev* 2005; 27(1): 1-8.
- 124 *Issue Brief: The Elements of Integrated Care Management*. Bloomington: National Chronic Care Consortium, 1995.
- 125 *Issue Brief: The Elements of Integrated Care Management*. Bloomington: National Chronic Care Consortium, 1995.

- 126 Centers for Disease Control and Prevention. *Promising Practices in Chronic Disease Prevention and Control: A Public Health Framework for Action*. Atlanta: Department of Health and Human Services, 2003.
- 127 <http://www.visn8.med.va.gov/v8/clinical/cccs/clinical/ClinicalModel.htm>
- 128 Michaels Fisher H, McCabe S. Managing Chronic Conditions for Elderly Adults: The VNS CHOICE Model. *Health Care Financ Rev* 2005; 27(1): 33-45.
- 129 Pepe MC, Applebaum RA. Ohio's options for elders initiative: cutting corners or the cutting edge? *J Case Manag* 1996; 5(1): 12-8.
- 130 Coon DW, Williams MP, Moore RJ et al. Northern California Chronic Care Network for Dementia. *J Am Geriatr Soc* 2004 Jan;52(1):150-6.
- 131 Hollander MJ, Pallan P. The British Columbia Continuing Care system: service delivery and resource planning. *Aging* 1995; 7(2): 94-109.
- 132 Ministry of Health Services. *Chronic Disease Management*. <http://www.healthservices.gov.bc.ca/cdm>
- 133 *A Framework for a Provincial Chronic Disease Prevention Initiative*. British Columbia: Population Health and Wellness, Ministry of Health Planning; 2003
- 134 *The Primary Health Care Strategy 2001*. Wellington: Ministry of Health, 2001.
- 135 Wellingham J. *Engaging At Risk Populations In Early Intervention Programmes*. Unpublished draft report for WHO, 2005.
- 136 *Value for Money in the Health System*. Unpublished discussion document. Wellington: Ministry of Health, 2005.
- 137 Homer J et al. *The CDC's Diabetes Systems Modeling Project: Developing a New Tool for Chronic Disease Prevention and Control*. 22nd International Conference of the System Dynamics Society. July 25-29, 2004. Oxford, England.
- 138 Care Plus - an Overview. Wellington: NZ Ministry of Health, 2005.
http://www.moh.govt.nz/moh.nsf/wpg_Index/Publications-Care+Plus+an++Overview
- 139 Wellingham J, Tracey J, Rea H, Gribben B. The development and implementation of the Chronic Care Management Programme in Counties Manukau. *NZ Med J* 2003; 116(1169):U327.
- 140 Australian Government Department of Health and Aging. *Draft National Chronic Disease Strategy*. Unpublished, 2005.
- 141 *NSW Chronic Care Program 2000-2003: Strengthening capacity for chronic care in the NSW health system*. Report on Phase one, Sydney: NSW Health, 2004.
- 142 *Preventing Chronic Disease: A Strategic Framework. Background Paper*. Melbourne: National Public Health Partnership, 2001.
- 143 *NSW Government Action Plan for Health. Improving health care for people with chronic illness. A blueprint for change 2001-2003*. Sydney: NSW Health, 2001.
- 144 *NSW Chronic Care Program 2000-2003: Strengthening capacity for chronic care in the NSW health system*. Report on Phase one, Sydney: NSW Health, 2004.
- 145 Macq J. Commentary: trials should inform structures and processes needed for tailoring interventions. *BMJ* 2005; 330: 665-6.
- 146 Cheah J. Chronic disease management: a Singapore perspective. *BMJ* 2001; 323: 990-3.
- 147 Goldberg A. Integrated system for chronic disease management. Can we apply lessons learned from France? *Chest* 2004; 125 (2): 365-7.
- 148 <http://www.dh.gov.uk/assetRoot/04/11/92/85/04119285.ppt#10>
- 149 Singh D. *Transforming Chronic Care in Surrey and Sussex. Where are we starting from?* Crawley: Surrey and Sussex PCT Alliance, 2005

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Long-term conditions: how to manage them?

The Department of Health defines long-term conditions as ‘diseases which current medical interventions can only control not cure’¹. These types of conditions create a unique challenge to both developing and developed countries. In this article, **Joanna Goodwin** discusses the different models of long-term care management that have already been established in the US and discusses whether they can be applied to the UK.

Globally, as infant mortality decreases and populations live longer, there is greater exposure to risk factors that can premeditate the development of long-term conditions, such as obesity and tobacco smoke². In the UK, 17.5 million people have a long-term condition³; the most common conditions being arthritis, heart disease and respiratory diseases¹. Older people are more likely to have multiple long-term conditions than their younger counterparts, and the risks of this increases as they age^{1,3}. Globally, 87 per cent of over 65 year olds have at least one long-term condition and 67 per cent have multiple conditions. These figures rise in the over 80 years age group – 92 per cent have one long-term condition and 73 per cent have more than one⁴.

Impact on healthcare resources

In the US, 83 per cent of the healthcare spending is for people with long-term conditions⁴. This is mirrored in the UK, where 80 per cent of General Practitioner (GP) consultations and 60 per cent of hospital bed days are associated with long-term conditions¹. Healthcare spending sharply rises as the number of long-term conditions increases^{1,3}, and the cost of long-term conditions does not only impact on health resources. For example in 1999, Coronary Heart Disease (CHD) was estimated to cost £7.06 billion in the UK, but only 25 per cent

of this was spent on direct healthcare with the rest spent on informal care costs and lost earnings due to ill health⁵.

This article will discuss the different models of long-term management that have been established in the US and look at whether these could be applied to a UK setting.

Chronic Care Model

The Chronic Care Model, introduced by Wagner in 2002, has gained authority and respect in the US⁶. Traditionally healthcare has been organised around the needs of acute, episodic care. However, an acute care model when applied to long-term conditions results in unnecessary, lengthy hospital admissions, a passive patient experience and costly healthcare⁷. In the Chronic Care Model, care is placed squarely in the primary care arena, facilitating secondary care only as necessary. This framework is then broken down into six building blocks of care: the organisation of health care, community resources, self-management support, delivery system design, decision support and clinical information systems⁷.

Long-term conditions and the NHS

The Department of Health (DoH) uses the Chronic Care Model in its policies such as

the National Service Frameworks (NSFs) for conditions such as CHD and diabetes, which have provided guidelines for management based on robust evidence. In addition, the General Medical Services GP contract has a funding stream dedicated to quality payments linked to long-term conditions. This ensures that the organisation of healthcare is focused on the provision of services to those with chronic illnesses⁸.

As well as using the Chronic Care Model, the DoH has adapted the Pyramid of Care from the Kaiser Permanente model (by the American healthcare insurance group^{1,3,9}) and used it in the NHS Improvement Plan⁹ and other documents. The base of the Kaiser Permanente model, which is discussed later on in this article, rests on population wide prevention of ill health and health promotion. Interestingly the Pyramid of Care does not appear in the DoH's most recent document, *The NSF for Long-term Conditions*¹⁰.

The Pyramid of Care

Level one of the pyramid consists of supported self-care; it is anticipated that 70 to 80 per cent of the long-term condition population will be managed this way. This involves education about their condition, the knowledge to manage changes in their health and the importance of taking medication as prescribed. Effective support includes improving the individual's confidence and capacity to become an active partner in managing their long-term condition¹¹. One method of facilitating this is via the Expert Patient Programme. This is led by a non-medical leader and people who have a long-term condition themselves. This is an acknowledgement that disease management can be viewed too much in a medical model framework and that living with a condition provides a unique insight to its management¹².

Level two of the pyramid is disease-specific care management. People with complex needs relating to a particular condition are cared for in this way. Care is provided by multi-disciplinary teams, which have specialist knowledge of the appropriate condition, and care is based on evidence based guidelines and patient pathways using the NSFs and guidance produced by the *National Institute for Health and Clinical Excellence* (NICE)⁹. Individual studies have shown disease-specific care management can be effective, but the level of success varies between the severity

of the condition, mode of intervention and type of patient included¹³. This point is also very relevant when discussing case management.

Disease-specific management is generally presumed to be more cost effective than conventional care. The DoH expects long-term condition management to reduce emergency bed days and the resultant cost by five per cent by 2008³, but there is a scarcity of evidence on cost reductions from implementing care management, and available studies have methodological limitations. Also, studies often fail to capture the cost of implementing the intervention itself. Hidden costs include training of staff and cost of identifying and enrolling of patients. Thus, the Congressional Budget Office in the US finds that 'to date there is insufficient evidence to conclude that disease management programmes can generally reduce the overall cost of health care services'¹⁴.

Level three of the pyramid is case management. This is for the small percentage of patients who have multiple long-term conditions, whose complexity makes them high users of primary care, social care and unplanned hospital time. These patients are often older people and are particularly the oldest old. Case management is intensive, individualised and involves enduring care that evaluates medical and nursing needs as they rapidly change. It also takes a holistic view of health and social care to provide input centred on an individual^{1,3}.

Castlefields – Unique Care Model

This approach to case management started in 1999 in a health centre in Runcorn. The model involves a joint assessment by a social worker and nurse to address health and social care needs driven by the patient themselves. The team also proactively in-reaches into hospital to support discharge planning and has criteria to assertively access patients before crisis intervention is required¹⁵.

The Unique Care model sees itself as differing from the US models, by the increased skills of existing staff, rather than the implementation of a new team. The service has reported a 15 per cent fall in hospital admissions from a baseline in 1999 after four years and a reduction in bed occupancy of 41 per cent¹⁶. This evidence has not been published in a peer reviewed journal and is essentially based on evidence from one healthcare centre. Despite

this, the National Primary Care Development Team, a DoH support vehicle for Primary Care Trusts (PCTs), is advocating the countrywide uptake of the model.

Kaiser Permanente approach

Kaiser Permanente Medical Care Programme is a large managed care organisation with eight million members in the US. Their approach to long-term condition management can be seen from the Kaiser Permanente Pyramid of Care described earlier. They are proactively involved in all layers of care in the pyramid.

The organisation collects health insurance payments from members and then provides them with care. Physicians have an interest in minimising hospital stays because they share responsibility for the success of the programme; they also provide the clinical leadership for the organisation, rather than generic managers. Medical specialists also work alongside primary care generalists, so there is no incentive to have overlong hospital stays. In addition, there is integrated care across primary and secondary care, as Kaiser Permanente provide both care systems¹⁷.

Both the individual purchasing their health plan and large organisations bulk buying healthcare for their employees have effective levers on American healthcare providers. They are able to negotiate for lower cost, high quality services and to move between providers as they wish. This ensures that the organisation is competitive and responds quickly to clinical needs to provide prompt diagnosis and treatment¹⁸.

Feachem *et al*¹⁸ compared the cost and performance of the NHS to Kaiser Permanente in California. They found for relatively similar population characteristics, activities and cost, there were nearly four times the number of acute bed days in the NHS than for Kaiser Permanente per 1,000 population. Access of services was much quicker with the Kaiser Permanente model: 80 per cent of NHS patients referred to a consultant were seen in 13 weeks, compared with Kaiser Permanente where 80 per cent of patients were seen in two weeks. Feachem *et al*'s methodology has resulted in much critique and discussion, but the differences are stark.

Ham *et al*¹⁹ further explored this area; they analysed 11 common conditions and found that admission rates, length of stay and bed day use were higher for the NHS than for Kaiser Permanente. For example, length of stay for stroke and hip fractures was five to six times longer for NHS patients than for Kaiser Permanente patients¹⁹.

The application of the Kaiser Permanente system to the UK would not be possible in the US form. It is very much a

whole systems approach with specific drivers to ensure quality and efficiency. There are many points to learn, however, especially for the management of long-term conditions; for example, the emphasis on primary care and integration of care.

Evercare model

The UnitedHealthcare group model, Evercare, is based on five core principles: individualised, holistic person centred care; the use of primary care as the controlling, commissioning force; care provided in the least invasive setting; reduction in unnecessary polypharmacy; and lastly, a data feedback system to improve performance^{17,20}. These principles are echoed throughout more recent DoH publications^{3,9}.

Evercare implement these strategies via the use of Advanced Primary Nurses (APNs). Their role is one of 'generalist with special interests rather than specialists'¹⁷ or proactive generalists rather than reactive specialists²⁰. Abilities include physical examination, illness monitoring, close collaborative working with the GP and critical reasoning to provide the best care for their patients²⁰. The UnitedHealthcare group state that the Evercare US programme reduces hospital admissions by 50 per cent, decreases medication costs, is popular with enrollees and improves clinical practice²¹.

This is supported by a study by Kane *et al*²², but the paper raised some interesting points that certainly limit Evercare's potential to be applied to an UK setting. Firstly, in the US, the Evercare model is almost exclusively used in nursing home settings, so its application to community dwelling vulnerable adults is unproven. The study also found that Evercare was successful due to the use of Intensive Service Days. These were an incentive payment to the nursing home to provide any extra nursing support to prevent a hospitalisation. When hospitalisation and Intensive Service Days were counted together, Evercare admission rate was similar to the control groups²². The study unfortunately did not incorporate a cost analysis of the different patterns of care.

The DoH is currently piloting the Evercare model in 10 PCTs in the UK. This project is still under evaluation, but Evercare's own interim report summarises that the approach can successfully be applied to the UK. They state that they have identified a previously unidentified high-risk population, and have re-engineered the

nursing workforce and improved collaborative patient care²¹. They do not provide any statistics from the pilot sites, but give anecdotal examples of admission avoidance and reducing hospital stays²¹.

Research by the National Primary Care Research and Development Centre is currently evaluating the UK Evercare pilot sites and they identify some key flaws to the evidence produced²⁰. For example, one of the central themes to the Evercare model is its identification of high-risk people who would benefit from case management. One of the main methods by which this is carried out is identifying older people who have had two or more unplanned hospital admissions in the last year. The report analysed the Hospital Episode Statistics and found that the number of admissions for these people fell in the next year. In the year in which they are identified, people who would meet the criteria for the Evercare programme were responsible for 38 per cent of hospital admissions. In the following year they were responsible for 10 per cent of admissions, and this drops to six per cent of admissions the year after²¹. It is not known why this is at present (possibly because admission to permanent care plays a large factor) but it highlights that although a previous unplanned admission is a risk factor for a future admission, it is one of poor predictive value. Evercare or any other case management model should not therefore use unplanned admissions as their main recruiting grounds for case management.

This limited effect on unplanned hospital admissions will be the same for other case management programmes who base their patient identification on previous hospital admissions. Thus, for a scheme to prove its efficacy it would need to include a control group as a comparison, rather than rely on a decrease in hospital admissions²⁰. UnitedHealthcare Group start to acknowledge this within their more recent final report²³. They explain some of the drop in hospital admissions as a 'regression toward the mean'. That is the extreme population selected, i.e. those with two or more unplanned admissions, are likely by chance to be less extreme when measured in the future. This confusing explanation would only be clarified by the gold standard of a randomised controlled trial²³.

It is unlikely that Evercare UK will be as successful as the US model due to the community dwelling population and lack of Intensive Service Days.

The evidence base for case management

As discussed, the above schemes have not produced independent research based on a randomised controlled trial format to support their case management programmes. There has, however, been a variety of studies undertaken on case management outside of these organisations. The NHS management centre's rapid review 'found inconsistent evidence of the effects of case management on quality of care, clinical outcomes and healthcare resource use from 11 systematic reviews, 19 additional randomised trials and four other studies²⁴'. The King's Fund report further broke this down to identify weak evidence for case management to prevent hospital admissions, no decrease in emergency department use, some decrease in length of hospital stay and modest improvement in functional abilities²⁵.

Limited work has also been done to identify the successful components of case management programmes. Stuck *et al* found that the effects of the intervention varied considerably dependent on the skills and abilities of the case manager providing the care. One nurse identified fewer problems than the other two nurses and subsequently did not have the same effect on reducing nursing home admissions and improving functional abilities of the patients seen²⁶. Gagnon *et al* identified the lack of authority and credibility of the case managers as the reason for their insignificant findings²⁷.

Counter-intuitive results have also been found with regards to medication review, which is a core component of case management schemes. Holland *et al* found that a medication review by a pharmacist following discharge from hospital actually increased readmission rates to hospital by 30 per cent and increased GP home visits by 43 per cent²⁸. Their initial analysis of these findings suggest that patients may have had more knowledge of their conditions and may have self-referred themselves to services when unwell or that due to better adherence to medications, they may have inadvertently triggered iatrogenic illnesses²⁸.

The community matron

The DoH has placed the responsibility for case management onto a new healthcare professional – the community matron. This professional will co-ordinate complex needs across health and social care, to pro-actively manage problems before they

lead to poorer health or hospitalisation⁹. The NHS Improvement Plan states there will be over 3,000 community matrons by 2008⁹. This new role is very much modelled on the APN from the Evercare scheme²⁹.

The community matron will take responsibility for around 50 to 80 patients, develop a personalised care plan and monitor the individual regularly^{9,29}. They will have advanced roles, such as managing medications, including prescribing and ordering investigations²⁹. It is anticipated that district nurses will be the most appropriate existing staff group to take on this role²⁹. This however could lead to staff shortages in this branch of nursing, which currently struggles with recruitment and retention problems³⁰. This has been found to be a problem in the Evercare pilot sites, where there were delays in backfilling posts and some nurses trying to attempt both roles²¹. It is also thought that the DoH has been too specific in identifying only nurses for this role. Occupational therapists or community physiotherapists would also be well placed to take on this role.

Conclusion

We can trace the DoH's response to the looming crisis of long-term conditions management through US processes such as the Chronic Care Model, Kaiser Permanente's pyramid of care and Evercare's use of APNs. It is, however, simplistic to think that these tools, in particular case management, will revolutionise the care of people struggling with long-term conditions without whole system change and significant drivers to improve care ■ GM

Conflict of interest: None declared

Key points

- > In the UK, 17.5 million people have a long-term condition.
- > The US Chronic Care model and the Kaiser Permanente Pyramid of Care can be seen throughout DoH literature on the management of long-term conditions.
- > The role of the Community Matron has been championed by the DoH, despite different models of case management providing weak or inconclusive evidence to their efficacy in the UK healthcare system.

References

1. Department of Health. Chronic Disease management: A compendium of information 2004. <http://www.natpact.nhs.uk/uploads/Chronic%20are%20Compendium.pdf> (date last accessed: 14/12/05)
2. World Health Organisation. Innovative Care for Chronic Conditions: Building Blocks for Action 2002. www.who.int/chronic_conditions/en/icccglobalreport.pdf (date last accessed: 14/12/05)
3. Department of Health. Supporting People with Long Term Conditions. An NHS and Social Care Model to support local innovation and integration 2005. <http://www.dh.gov.uk/assetRoot/04/12/25/74/04122574.pdf> (date last accessed: 14/12/05)
4. Partnership for Solutions. Chronic Conditions: Making the Case for Ongoing Care 2004. <http://www.partnershipforsolutions.com/DMS/files/chronicbook2004.pdf> (date last accessed: 14/12/05)
5. World Health Organisation. Towards a European strategy on noncommunicable diseases 2004. <http://www.euro.who.int/document/rc54/edoc08.pdf> (date last accessed: 14/12/05)
6. Bodenheimer T, Wagner E, Grumbach K. Improving Primary Care for Patients with Chronic Illness. *Journal Of the American Medical Association* 2002; **288**: 1775–79
7. Holman H, Lorig K. Patients as partners in managing chronic disease. *BMJ* 2000; **320**: 526–2
8. NHS Confederation. GMS contract negotiations fact sheet - The quality and outcomes framework 2003. <http://www.nhsconfed.org/docs/factsheet1.pdf> (date last accessed: 14/12/05)
9. Department of Health. The NHS Improvement Plan: Putting People at the Heart of Public Services 2004. www.dh.gov.uk/assetRoot/04/08/45/2/04084522.pdf (date last accessed: 14/12/05)
10. Department of Health. The National Service Framework for Long-term Conditions 2005.
11. Department of Health. Self Care - A Real Choice 2005. <http://www.dh.gov.uk/assetRoot/04/10/17/02/04101702.pdf> (date last accessed: 14/12/05)
12. Department of Health. The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century 2001. <http://www.dh.gov.uk/assetRoot/04/01/85/78/04018578.pdf> (date last accessed: 14/12/05)
13. Weingarten S, Henning J, Badamgarav E, *et al.* Interventions used in disease management programmes for patients with chronic illness - which ones work? Meta-analysis of published reports. *BMJ* 2002; **325**: 925–31
14. Congressional Budget Office. An Analysis of the Literature on Disease Management Programs 2004. <http://www.cbo.gov/ftpdocs/59xx/doc5909/10-13-DiseaseMngmnt.pdf> (date last accessed: 14/12/05)
15. National Primary Care Development Team. Chronic Disease Management: Unique Care 2004. <http://www.npdt.org/15/Unique%20Care.pdf> (date last accessed: 14/12/05)
16. Dix A. Happy Ever After. *Health Service Journal* 2004; 28–31
17. Matrix research and consultancy. NHS Modernisation Agency. Learning distillation of Chronic Disease Management programmes in the UK 2004. www.natpact.nhs.uk/uploads/Matrix%20CDM%20Evaluation%20Report.doc (date last accessed: 14/12/05)
18. Feacham R, Sekhri N, White K. Getting more for their dollar: a comparison of the NHS with California's Kaiser Permanente. *BMJ* 2002; **324**: 135–43
19. Ham C, York N, Sutcliffe S, Shaw R. Hospital bed utilisation in the NHS, Kaiser Permanente, and the US Medicare programme: analysis of routine data. *BMJ* 2003; **327**: 1257–61
20. National Primary Care Research and Development Centre. Evercare evaluation interim report: implications for supporting people with long-term conditions 2005. www.npcrdc.man.ac.uk/Publications/evercare%20report1.pdf (date last accessed: 14/12/05)
21. UnitedHealth Group. Implementing the Evercare Programme. Interim Report 2004. www.natpact.nhs.uk/cms/186.php (date last accessed: 14/12/05)
22. Kane R, Keckhafer G, Flood S. The Effect of Evercare on Hospital Use. *Journal of the American Geriatrics Society* 2003; **51**: 1427–34
23. UnitedHealth Group. Assessment of the Evercare Programme in England 2003–04. www.unitedhealthgroup.co.uk/downloads/executive-summary.pdf (date last accessed: 14/12/05)
24. Singh D, Health Services Management Centre, University of Birmingham. Transforming Chronic care: Evidence about improving care for people with long-term condition 2005. www.hsmc.bham.ac.uk/news/Transforming%20Chronic%20Care%20JA%202005.pdf (date last accessed: 14/12/05)
25. Kings Fund. Case-Managing Long-Term Conditions: What impact does it have in the treatment of older people? 2005. http://www.kingsfund.org.uk/resources/publications/case_managing.html (date last accessed: 14/12/05)
26. Stuck A, Minder C, Peter-Wuest I, *et al.* A Randomised Trial of In-Home Visits for Disability prevention in Community-Dwelling Older People at Low and High Risk for Nursing Home Admission. *Archives of Internal Medicine* 2000; **160**: 977–86
27. Gagnon A, Schein C, McVey L, Bergman H. Randomised Controlled Trial of Nurse Case Management of Frail Older People. *Journal of the American Geriatrics Society* 1999; **47**: 1118–24
28. Holland R, Lenaghan E, Harvey I, *et al.* Does home based medication review keep older people out of hospital? The HOMER randomised controlled trial. *BMJ* 2005; **330**: 293
29. Department of Health. Supporting People with Long Term Conditions: liberating the talents of nurses who care for people with long term conditions 2005. www.dh.gov.uk/assetRoot/04/10/24/98/04102498.pdf (date last accessed: 14/12/05)
30. Morrison J. Identifying People at High Risk of Emergency Hospital Admission. *BMJ* 2005; **330**: 266



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**By: Health
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Division of
Health
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and Public
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ROADMAP

Strengthening people- centred health systems in the WHO European Region

**A Framework for Action
towards
Coordinated/Integrated
Health Services Delivery
(CIHSD)**



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Strengthening people-centred health systems in the WHO European Region

A Framework for Action towards Coordinated/Integrated Health Services Delivery (CIHSD)

**By: Health Services Delivery Programme,
Division of Health Systems and Public
Health**

ABSTRACT

The proposed Framework for Action towards Coordinated/Integrated Health Services Delivery (CIHSD) draws on the Regional Director's (RD) vision and that of Health 2020 for strengthening health system performance through innovative approaches to modernize and transform the delivery of services in order to better respond to the health challenges of the 21st century. The purpose of this document is to provide an overview of the core phases and respective processes in developing a Framework for Action towards CIHSD. The Roadmap at hand is intended as a planning tool to guide this process, generating discussion and facilitating opportunities for pragmatic collaborations and consultations throughout the phases and processes defined. In giving structure to the technical work on CIHSD at the WHO Regional Office for Europe, the Roadmap aims also to ensure the improved coherence of ongoing and future products and to maximize the relevance of this work for Member States. This Roadmap document is divided into five sections, giving a narrative to the following: (1) a brief overview of the coordination/integration of health services delivery looking to key definitions, concepts, and evidence available in the literature; (2) the context of the European Region to which this work plan intends to respond including the experiences of Member States and related work of the Regional Office to-date; (3) the envisioned Framework for Action towards CIHSD – its objectives, technical framework and expected outcomes and impact; (4) the specific phases and processes for its development; and (5) a description of key partnerships necessary to ensure this process is participatory and guided by continuous consultations with Member States, across in-house divisions and with external experts.

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PREFACE

[Aims of Health 2020] *“To significantly improve the health and well-being of populations, reduce health inequalities, strengthen public health and ensure people-centred health systems that are universal, equitable, sustainable and of high quality”* (WHO Regional Office for Europe, 2012a).

Building on the vision of current and earlier global commitments¹, a World Health Organization (WHO) global strategy to towards high quality, people-centred and integrated care is currently being developed. With the aim of universal health coverage – a continued priority expressed most recently just this past May (2013) at the 66th World Health Assembly (see resolution WHA66.23) – the strategy calls for strong health systems to provide a range of quality, affordable services and at all levels and sites of care. Taking an evidence-informed, forward-looking approach, the strategy intends ultimately to support WHO, its Regional Offices and its Member States in tackling persisting health system barriers that continue to limit the availability of services and lack of people-centredness in the delivery of care.

In the WHO European Region, efforts at present for health system strengthening (HSS) are guided by the new European health policy, Health 2020, committing Member States to achieve the Region’s health potential by year 2020 (WHO Regional Office for Europe 2012a). The umbrella policy framework places great importance on HSS as one of its four priority areas, recognizing the unique responsibility of health systems to deliver services that improve, maintain or restore the health of individuals and their communities. This priority importantly recalls the commitments set out in the 2008 Tallinn Charter – a milestone for the European Region, marking the importance that Member States place on improving the performance of their health systems and the direct relation between this and secured gains in population health and wealth (RC/EURO 2008).

Highlighting the importance of people-centred and integrated care, the European Union has recently launched initiatives aiming in the same direction. The European Innovation Partnership on Active and Healthy Ageing (EIP AHA, European Commission 2012), and the health research priorities defined in the FP7 research programme (European Commission 2005), all work towards transformed and strengthened health systems in line with the Europe 2020 strategy (European Commission 2010). Research and innovation in this area will further be strengthened by the new framework programme Horizon 2020 (European Commission 2011). As has the World Health Organisation, so has the European Union recognized the need for a pro-active approach to help its member states strengthen their health systems, and enable its citizens to lead healthy and self-determined lives in line with the life-course approach. Hence, Europe 2020 and Health 2020 will logically complement each other, while adapting to the needs of its respective member states.

Central to improving the performance of health systems are transformations in how services are delivered. This is recognized in the operational approach to HSS of the Division of Health Systems and Public Health (DSP), ensuring the removal of health system bottlenecks that effect

¹ Recalling the Declaration of Alma-Ata (1978), resolutions such as WHA54.13, WHA56.6 and WHA62.12 and summits on health system strengthening such as the International Conference dedicated to the 30th Anniversary of the Alma-Ata Declaration on primary health care (Almaty, 2008).

coverage of core services in a given priority health area (WHO Regional Office for Europe 2012b). Moreover, transforming the delivery of services is a fundamental component in a number of strategies across technical Divisions at the Regional Office². Importantly, a core tenet of these efforts is strengthening the coordination/integration of care such that the provision of health services is organized according to the needs and expectations of the individual, overtime and across the full continuum of care.

It is in response to needed transformations in the delivery services and in the context of the guiding commitments described above that the Framework for Action towards Coordinated/Integrated Health Services Delivery (CIHSD) has been conceived. The Roadmap document at hand is envisioned as a planning tool to communicate the processes to achieving the Framework for Action towards CIHSD by 2016. In the sections to follow, the concepts and context surrounding this work plan are further described, with priority then given to defining the phases, processes and products as well as key partnerships and a timeline for these efforts from the present until the final presentation of this work for Member State endorsement.

² This includes the WHO European Regional Action Plan to Strengthen Public Health Capacities and Services (RC62, Malta); the WHO European NCD Action Plan (RC61, Baku); the Regional Action Plan to Prevent and Combat MDR-TB and HIV (RC61, Baku); and the Strategy and Action Plan for Healthy Ageing in Europe 2012 – 2020

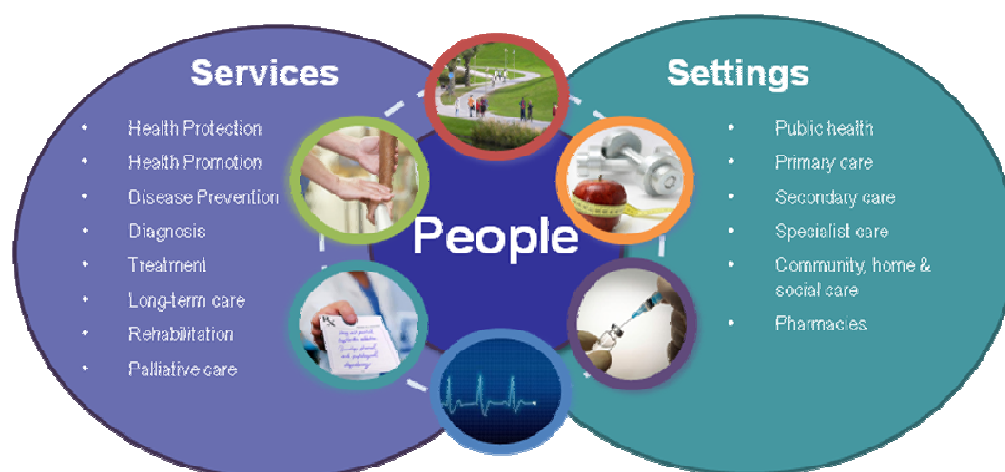
SECTION ONE: THE COORDINATION/INTEGRATION OF HEALTH SERVICES DELIVERY – IN BRIEF

1.1 Defining people-centred, coordinated/integrated health services delivery (CIHSD)

Coordinated/integrated health services delivery (CIHSD)³ is defined here as the management and delivery of health services such that people receive a continuum of health promotion, health protection and disease prevention services, as well as diagnosis, treatment, long-term care, rehabilitation, and palliative care services through the different levels and sites of care within the health system and according to their needs (adapted from PAHO, 2011). Viewed along a continuum – rather than as two extremes of integrated or not integrated – the CIHSD itself can then be described as a process or tool, serving as a means to secure gains in quality, efficiency and continuity of care and ultimately; to achieve improvements in health status and equity outcomes.

According to the above definition and in its simplest form, efforts towards the CIHSD must consider the services provided and the settings of care, and further, the alignment of the two according to the unique health needs of a given individual (Figure 1.1.1). As shown below, in order to ensure truly people-centred services, priority must be given to provide the “right services” in the “right place” (settings) through strategic processes that allow the complementary and coordinated delivery of services through the lens of an individual and their respective needs and preferences.

Figure 1.1.1 Coordinated/integrated health services delivery defined



Importantly, we note the services considered span the full spectrum of care, encompassing from the essential public health operations (EPHOs) of health protection (EPHO 3), health promotion (EPHO 4) and disease prevention (EPHO 5) to diagnosis, treatment, long-term care, rehabilitation and palliative care. Thinking to the settings of care along this continuum of services, these cut across varied levels and sites to include the broad scope of public health at the

³ We use ‘coordinated/integrated’ recognizing the translation of ‘integrated’ into Russian poses interpretation challenges, holding a different connotation and meaning to that intended here. ‘Coordinated’ is then used in combination merely for translation purposes and not to suggest a second meaning to the concept of ‘integrated health services delivery’.

population and individual level, the central setting of primary care, referrals to secondary care and specialist care, as well as the continuous support of community, home and social care settings and linkages across these settings with pharmacies.

The specific approaches or processes employed creating the linkages between the services and settings may draw from across the health system. This includes for example, efforts to redesign or support the existing workforce in the clinical provision of services, the alignment of incentives to enable and promote the coordination of care across providers, structures to continuously measure the level of system integration, as viewed by objective and subjective people-centred parameters, or an investment in the infrastructure needed to support a shared information system. Redesign efforts also need to consider new professional roles and the skills necessary to work in this changed environment. Strengthening the CIHSD as depicted above is then an effect of the harmonious alignment of services and settings of care through the strategic use of processes that work to manoeuvre the system towards more integrated services.

1.2 Defining related key concepts of CIHSD

The extent to which services along the full continuum of care are experienced in a coordinated/integrated manner can be depicted from the perspective of an individual him/herself. This perspective is described by the concept of continuity of care defined as, “the degree to which a series of discrete health care events are experienced by people as coherent and interconnected over time, and consistent with their health needs and preferences” (PAHO 2011, p. 29).

Focused on providing the ‘right care’ in the ‘right place’, CIHSD aligns with the WHO Regional Office for Europe’s priority of people-centred health systems – systems in which care is focused and organized around the health needs and expectations of people and communities, rather than on diseases themselves (WHO Regional Office for Europe 2012a; WHO 2010). People-centred care is broader than the closely-related concept of patient-centred care. Whereas patient-centred care focuses on the individual seeking services – the patient – people-centred care encompasses these encounters with the health system while also including attention to the health of people in their communities and the crucial role of citizens in shaping health policy and services (WHO Regional Office for Europe 2012a; WHO 2010). Thus, a people-centred approach takes a unique orientation that is able to recognize that before people become patients, they need to be informed and empowered in promoting and protecting their own health.

Table 1.2.1 below further notes the distinction between conventional (patient-centred) care and disease-specific programmes, with that of the broad, all-encompassing scope of people-centred health services delivery.

Table 1.2.1 Distinguishing features of people-centred care

Conventional care	Disease-specific programmes	People-centred care
Focus on illness and cure	Focus on priority diseases	Focus on health needs
Relationship limited to the moment of consultation	Relationship limited to programme implementation	Enduring personal relationship
Episodic curative care	Programme-defined disease control interventions	Comprehensive, continuous and person-centred care
Responsibility limited to effective and safe advice to the patient at the moment of consultation	Responsibility for disease-control targets among the target population	Responsibility for the health of all in the community along the life cycle; responsibility for tackling determinants of ill-health and maintaining health
Users are consumers of the care they purchase	Population groups are targets of disease-control interventions	People are partners in managing their own health and that of their community. Their preferences and motivations are integrated into care planning.

Source: (WHO 2008a)

Other key concepts include that of integrated health care networks, introduced by PAHO as a network of organizations that provide or arrange health services in a coordinated continuum to a defined population and are willing to be held clinically and fiscally accountable for the outcomes and health status of the population served (2011). Integrated health care networks – like the CIHSD as described here – are seen not as an aim in themselves, but rather a means to improve coordination of care and hence, care continuity, quality and efficiency (Table 1.2.2).

Table 1.2.2 Key concepts defined

Integrated health services	Continuity of care	People-centred care	Integrated health care networks
"The management and delivery of health services such that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, through the different levels of care, and according to their needs throughout the life course" (PAHO 2011).	"The degree to which a series of discrete health care events are experienced by people as coherent and interconnected over time, and are consistent with their health needs and preferences" (PAHO 2011, adapted from Haggerty et al 2003).	"Care that is focused and organized around the health needs and expectations of people and communities rather than on diseases" (WHO 2010).	"A network of organizations that provides, or makes arrangements to provide equitable, comprehensive and integrated health services to a defined population and is willing to be held accountable for its clinical and economic outcomes and for the health status of the population that it serves" (PAHO 2011, adapted from Shortell et al. 1993).

1.3 What are the aims and benefits of CIHSD?

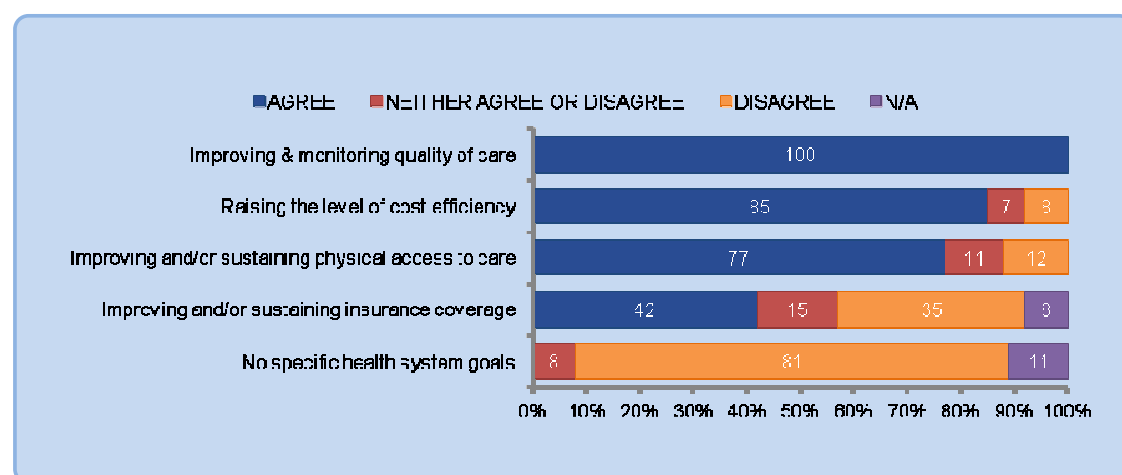
The coordination/integration of health services delivery is an approach to remove gaps in care or poor coordination in care that adversely effect care experiences and ultimately, health outcomes (Goodwin and Smith 2011). The overarching aim of CIHSD is then to overcome the challenges of fragmentation by creating linkages between services along the full continuum of care and to do so according to an individual's needs. Importantly, this does not mean that everything has to be integrated into one package, recognizing as Freeman et al. (2001) point out; discontinuities in

health care are likely inevitable. Rather, the aim is to ensure services are not disjointed from the perception of the service user and that each individual can easily navigate through the system's various levels and settings of care.

The potential benefits of more CIHSD can be viewed from the perspective of a number of health system stakeholders. For the public or patients, more coordinated/integrated services aim to provide a means to reverse or prevent the adverse outcomes of fragmented care, including the over-utilization of medicines, the reduction of redundant work, tests and procedures, adverse hospitalizations and medical errors (RAND 2012). The CIHSD has additionally been said to contribute to ensuring the following: the coordinated transfer and use of information by providers; the empowerment of citizens; improved access to appropriate services; individualized care; consistency in personnel; and a fluid patient-provider relationship (Waibel et al. 2011). For providers and the system-at-large, the coordination/integration of services can contribute to a reduction in the length of hospital stays, decreases in unnecessary hospital admissions and lower numbers of admissions to long-term care (Reed et al. 2005).

As a multi-country questionnaire conducted by the OECD finds, there is overwhelming agreement that policy discussions on the coordination/integration of services are most closely linked with aims to improve the quality of care (Hofmarcher, Oxley, and Rusticelli 2007) (Figure 1.3.1). This by extension impacts on health outcomes and the responsiveness of services to patient needs. To a lesser degree, the questionnaire finds the goals of cost efficiency and ensuring access to services drive the integration of care agenda.

Figure 1.3.1 Main goals of policies to improve care coordination



Source: OECD questionnaire on coordination of care 2006, N=26 (Hofmarcher, Oxley and Rusticelli 2007)

1.4 What might CIHSD look like in practice?

A continuously growing literature base has allowed a cataloguing of a range of examples of how CIHSD might be adopted in practice. Some of these initiatives falling under the integration of health services umbrella are outlined below (Figure 1.4.1) aligned with the following orientations common to their approach: system (re-)design in the delivery of services; support and shared information among professionals; improved information integration through the use

of modern technologies (e.g. clinical registries and patient records); and self-management or patient integrated care towards individual empowerment of their personal health needs.

Figure 1.4.1 Examples of initiatives towards the CIHSD

Delivery system design	Decision supports	Information systems	Self-management
<ul style="list-style-type: none"> ✓ Revision of professional roles ✓ Case/care manager ✓ Multidisciplinary teams ✓ Nurse-led clinics ✓ Follow-up by home visits ✓ Continuous evaluation 	<ul style="list-style-type: none"> ✓ Implementation of evidence-based guidelines, protocols, care plans ✓ Standardized education/trainings ✓ Distribution of educational materials among professionals 	<ul style="list-style-type: none"> ✓ Reminder systems ✓ Shared clinical records ✓ Audit and feedback of provider performance ✓ Register of health/social care service users 	<ul style="list-style-type: none"> ✓ Patient education and training ✓ Patient motivational counseling ✓ Distribution of educational materials ✓ Use of mHealth and eHealth tools

Source: Adapted from Nolte & McKee 2008, citing Zwar et al. 2006

The specific ‘integrating initiatives’ employed and their strategic combination are very much dependent on the constraints of the existing system and path dependencies, rather than a prescriptive framework or model of services delivery (Powell Davies et al. 2008; RAND 2012; Nolte and McKee 2008). As such, the CIHSD is not likely to follow a single path and variations and changes overtime are to be anticipated (WHO Regional Office for Europe Unpublished).

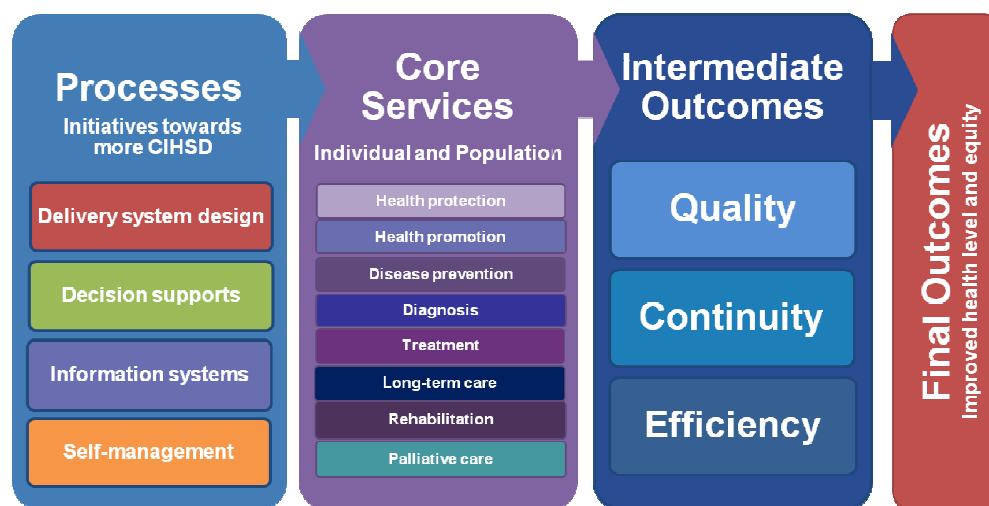
1.5 Improving health outcomes through the CIHSD

The transformation of services towards more coordinated/integrated care is best seen as a means to health system strengthening, rather than as an end in itself. The effects of these transformations are captured below (Figure 1.5.1), depicting the following cascade of relations: (1) the strategic and purposeful use of initiatives towards the CIHSD serve as the entry points to rethinking the delivery of services – applied as individual efforts or in combination with one another. These processes share in their common aim to ensure services are perceived as connected and coherent according to a given individual or service user. (2) The context to which these processes must align is defined by the structure of the health system and must span the full continuum of services as shown below, while also considering the interface between these and varied settings of care – from public health services, primary, secondary and specialist care, to the broader setting of community, social and home care services and the cross-cutting role of pharmacies. (3) In removing health system bottlenecks and barriers through the processes applied linking across core services and settings of care, it may then be possible to secure improvements in the quality, continuity and efficiency of health services delivery (intermediate outcomes) and ultimately in population health level and equity (final outcomes).

We note of particular importance and unique to this approach to HSS through the transformation of services for more CIHSD is the ability to ensure services are delivered in accordance to an

individual's needs and preferences. Improved continuity of care as an intermediate outcome is exclusive to this approach and thus, places the CIHSD as a key priority in order to secure high quality, people-centred health systems that are efficient in the delivery of services, according to the context (epidemiological, demographic, fiscal, environmental factors etc.) to which they must respond.

Figure 1.5.1 Improving health outcomes through the CIHSD



Source: Adapted from WHO Regional Office for Europe 2012b

1.6 What does the evidence say?

There is now a wide range of evidence on specific interventions or initiatives towards more CIHSD. This literature base agrees with growing consensus as to the potential for positive outcomes to be secured for the quality and continuity of care. Commonly cited gains include improvements concerning hospital utilization, quality of life, functional health, patient satisfaction and on process outcomes, such as adherence to guidelines and compliance with medication (Ouwens et al. 2005). Further identified advantages include improved access to appropriate levels of care (Ovretveit 2011; Banks 2002), as well as better individual experiences with care received (Ovretveit 2011). Importantly, the evidence does suggest that the impact of coordinated/integrated services may vary according to the pathology under consideration, and thus caution should be taken when interpreting and generalizing gains.

Some examples of these main messages from the literature and specific studies or contexts in which gains have been reported are described in Box 1.6.1 to follow.

Box 1.6.1 Evidence on the CIHSD – examples from the literature

- **Decreased hospitalizations, length of hospitalization or hospital readmissions.** In the United Kingdom (UK), a reduction of up to 27% in total number of day beds for emergency admissions for chronic illnesses between 2007 – 2009 was observed following integrated care pilots for people living with multiple chronic illnesses (Goodwin and Smith 2011).
- **Improved patient compliance and patient knowledge about their condition.** A review of a collaborative model programme for chronic health failure finds patients of providers participating in the programme were more knowledgeable, used recommended therapies more often and visited the emergency department less than those not participating in the model for more CIHSD (Coleman et al. 2009).
- **Improved patient satisfaction.** A review of integration studies (n=85) finds an overall increase in service-user or patient satisfaction in 45.2% of cases. The greatest improvements were secured in patient health outcomes (55.4% of cases), with least improvements in cost-savings (Powell Davies et al. 2008).
- **Improved access to appropriate health services.** An urgent care-tracking dashboard in the primary health care setting of the UK NHS observed a decrease in hospital admissions by 3% against a regional increase of 9% (Goodwin and Smith 2011). Unscheduled hospital admissions additionally fell by 4%.
- **Gains in cost-efficiency [inconsistent data].** A systematic review found that clinical coordination can save money, however, it depends on which approach is used, how well it is implemented, and on the features of the environment in which a provider is operating, including the financing system (Ovretveit 2011). Ultimately, short-term cost increases are to be anticipated, estimated in a study on improving diabetes care coordination as an additional \$6-\$22 per patient in the first year of implementation (via expenses related to the redesign of services) (Huang et al. 2008).

Evidence is also available capturing the gains of more CIHSD from the perspective of the individual service user and health care provider. For example, a meta-synthesis of qualitative studies on continuity of care suggests some positive outcomes when continuity is perceived in the delivery of services (Waibel et al. 2012). When there is consistency in health providers (relational continuity), users report that they receive the right information at the right time and in a sensitive manner. Furthermore, seeing the same provider is found to improve care plans, support the mutual understanding of needs and encourage a sense of responsibility for an individual's health status (Waibel et al. 2012). In addition, a systematic review of the association between continuity of care and outcomes strongly suggests that increased provider continuity is associated with improved health utilization and user satisfaction outcomes (van Walraven et al. 2010). Box 1.6.2 captures directly from the patient or provider some of their experiences with more CIHSD.

Box 1.6.2 Patient & provider perceptions of coordinated/integrated services

“The main services here are all routine, so we know when doctors are here and we can meet anyone we need to. We feel like there are people who really care about us here.”

(Service user, integrated HIV and services for injection drug users, Kriviy Rig Narcological Dispensary, Ukraine)^a

“The visits with the GPs are more regular and by seeing them with more regularity, there is more trust.”

(Service user, integrated care network for chronic obstructive pulmonary disease, Catalonia)^b

“My GP knows, without having to look at the computer, he knows what illnesses I suffer from and from which I don’t.”

(Service user, integrated care network for chronic obstructive pulmonary disease, Catalonia)^b

“Multidisciplinary teams allow us to have much more control over our patients care, with much better and more regular follow-up.”

(Provider, Crimean Republican Narcological Dispensary, Simferopol, Ukraine)^a

“Very often they (primary care providers) call me or send me an e-mail when they have a problem. I think that’s agile and communication exists, and above all it’s easy to realize.”

(Pulmonologist, integrated care network for chronic obstructive pulmonary disease, Catalonia)^b

Sources:

^aCurtis, M. 2010. *Building integrated care services for injection drug users in Ukraine*. Copenhagen: WHO Regional Office for Europe.

^bWaibel, et al. 2013. *The performance of integrated healthcare networks: analysis of continuity of care.* (In review).

SECTION TWO: CONTEXT OF CIHSD IN THE REGION

2.1 Regional trends driving the CIHSD agenda

Health services need to continuously adapt to emerging changes and central to improving the performance of health systems are transformations in how these services are delivered. At present, a number of factors are found to drive the needed transformations in services delivery across the European Region. These factors are understood importantly to include the following: shifting population demographics, as the population in the European Region is living longer than ever before with a life expectancy at birth among Member States averaging 76.6 years in 2011, while fertility rates continue to fall (averaging 1.64 in 2011) (WHO Regional Office for Europe 2012c); a rise in non-communicable diseases (NCDs) and related multi- and co-morbidities, with NCDs accounting for the largest proportion of mortality and premature death (approximately 87 percent of all deaths annually) (WHO Regional Office for Europe 2012c); the persisting challenge to control the spread of emerging and re-emerging communicable diseases, including HIV-infection and tuberculosis as well as those triggered by the changing environment and patterns of movement (thinking to international travel and migration) that heighten the international threat to health security through the spread of vaccine-preventable, foodborne and zoonotic diseases; and finally, the increasing expectations of citizens as education levels continue to rise and information becomes more readily available (Kickbusch & Gleicher 2012).

A misalignment between these challenges of today and existing models of care has subjected services to obstacles including the overuse, underuse and misuse of services, uncoordinated arrangements in the delivery of care, a bias towards acute treatment and the neglect of preventative and social care (WHO Regional Office for Europe Unpublished). Furthermore, a number of shortcomings in the structure and function of health services delivery persistently undermine progress towards people-centred, coordinated/integrated services. This includes a disproportionate focus on specialist, tertiary care, which has become a major source of inefficiencies and inequalities in the delivery of health services across the Region (WHO Regional Office for Europe 2013c).

Fragmentation in the delivery of services and insufficient and ineffective coordination and communication between different levels and sites of care are enduring challenges in the delivery of services (WHO 2008a). Leading causes of fragmentation and poor coordination in the Region include: programmes targeting specific diseases, risks and populations without integrating into the health system (such as vertical HIV or TB-specific programmes) (Moore 2003); the decentralization of health services that fragment the level of care (WHO 2008a); an absence of incentives and financial policies conducive to strengthening the coordination of care (WHO Regional Office for Europe 2012a); and a lack of evidence-informed pathways for the whole continuum of a care episode (WHO Regional Office for Europe 2012a).

Importantly, in the context of the global financial crisis – felt to varying degrees across the Region – the challenges of social protection have been exacerbated. Moreover, in this era of continuous advancements in medical technology, there is added strain on already limited resources to implement even modest investments to overcome shortcomings in the structure of services delivery.

As summarized in Table 2.1.1 below, it is in the context of the incongruence between the health demands at present and the available resources dictated by existing service delivery structures that transformations in health services delivery have been necessitated.

Table 2.1.1 Main driving forces for health system reforms towards more CIHSD

Demand-side	Supply-side
<ul style="list-style-type: none"> • Demographic changes • Increasing burden of non-communicable diseases, multi- and co-morbidities • Persisting challenges to prevent and control emerging and re-emerging communicable diseases • Rising patient expectations • Changing global climate and threats to international health security 	<ul style="list-style-type: none"> • Fragmentation of services and sub-specialisation • Hospital centrism - diverting from PHC values and public health services • Resource constraints and rising costs • Advancements in technology • Growing evidence and awareness of the adverse impacts of fragmented care

2.2 Experience of Member States towards more CIHSD

Across the Region, reforms in the delivery of care towards more integrated services have widely emerged in acknowledgement of sustainability and quality concerns and the need for more equitable, comprehensive, integrated and continuous responses on the part of the health system. While the specific ‘integrating initiatives’ applied and their strategic combination are found to vary by a given context and a system’s related path dependencies, these efforts ultimately share in their aim to overcome the challenges of fragmentation in the provision and financing of health care services.

Examples of initiatives have been studied and catalogued by a number of sources (see for example, Nolte & McKee 2008; Zwar et al. 2006; Kodner & Spreeuwenberg 2002). We highlight a small sample of these below while attempting merely to acknowledge the diversity in approaches for each intervention according to their unique aims.

Table 2.2.1 Experiences of Member States towards more CIHSD

COUNTRY	AIMS	DESCRIPTION	OUTCOMES
Estoniaⁱ	<i>To fully integrate communication through a national electronic health record system, linking across levels and sites of care</i>	<ul style="list-style-type: none"> ▪ National electronic health record hosting over 3,000 e-services and companion health insurance system for claims, reimbursement and prescriptions ▪ Implementation costs equivalent to approx. \$10 USD per citizen 	<ul style="list-style-type: none"> ▪ Efficiency gains via the direct communication between institutions and providers ▪ Engagement of individual receiving care via personal health record, virtual medical center and mobile patient applications
Germanyⁱⁱ	<i>To implement integrated care pathways for selected treatments towards improved rehabilitation of patients for the return to work sooner</i>	<ul style="list-style-type: none"> ▪ Integrated contracting model for coordination between case managers, doctors, psychiatrists & physiotherapists ▪ Selected procedures (e.g. pain therapy); targeted population 	<ul style="list-style-type: none"> ▪ Patients treated through integrated networks found to return to work 72 days earlier than those treated through conventional care pathways

COUNTRY	AIMS	DESCRIPTION	OUTCOMES
Hungary ⁱⁱⁱ	To coordinate the delivery of services and collaboration of providers in primary care	<ul style="list-style-type: none"> Capitated budget for participating group practices to cover all primary care services of a given population Incentives for prevention services and retained savings of practices for reinvestment 	<ul style="list-style-type: none"> Improved collaboration among providers Decrease in inappropriate services Increased attention to preventive services
Israel ^{iv}	To provide an integrated network of hospitals, primary and specialized clinics and pharmacies towards high quality, people-centred care	<ul style="list-style-type: none"> Services adapted to unique population sub-groups Prioritize innovative care models targeting continuity of data, care transition, & strengthening hospital-community care linkages 	<ul style="list-style-type: none"> Improvements in preventing hospital readmission Strong continuity of care via attention to patient preferences and home and community support systems in place Marked and sustained reduction in health and healthcare disparities
Ukraine ^v	To develop integrated services for people with a history of injection drug use as part of the country's ongoing response to the HIV epidemic	<ul style="list-style-type: none"> Integrated harm reduction and HIV treatment programmes Innovations including pharmacy-based needle exchanges, overdose prevention services, new programmes targeting stimulant users, and improved case management services 	<ul style="list-style-type: none"> Improved HIV treatment outcomes while also reducing illicit drug use through improved adherence to treatment and retention in care Improved user satisfaction

Notes: i. For further information, see for example: Estonian eHealth Foundation (2013). *Health information system*. Retrieved from <http://www.e-tervis.ee/index.php/en/health-information-systems>.
ii. Initiative of Techniker Krankenkasse – Statutory health insurer. See for example: Wagner, C. (2012). *Lessons from German: Implementing integrated care as a statutory health insurer*. London: The Kings Fund.
iii. For further information, see for example: Evetovits (2011). *Exploring new ways to pay health providers and improve performance*. Barcelona: WHO Barcelona Office for Health System Strengthening.
iv. Balicer, R. (2013). *Clalit health services*. (powerpoint) for the WHO Regional Office for Europe.
v. For further information, see for example: Curtis, M. (2010). *Building integrated care services for injection drug users in Ukraine*. Copenhagen: WHO Regional Office for Europe.

2.3 Challenges in reforming the delivery of health services

Marked gains of more CIHSD from across the Region have motivated continued efforts to initiate, implement and/or scale-up initiatives to transform services delivery. Moving this agenda forward at scale and pace, however, faces a number of challenges, summarized as follows:

- 1. Lacking capacity to scale-up location and/or disease specific initiatives.** Initiatives towards the coordination/integration of health services delivery are commonly driven by the local efforts of specific facilities or health care providers. While responding to the unique needs of a given sub-group of the population or a geographic area, these changes are often incremental, lacking the needed leadership and managerial capacity to bring efforts to scale.

To support those in leadership roles tasked with the management of these processes, an arsenal of policy tools and instruments are needed. This is of particular pertinence in the context of contemporary health systems, as the boundaries of the system have become increasingly blurred and the relationships and lines of accountability between actors – largely ambiguous.

- 2. Persisting health system bottlenecks.** Incremental changes ultimately do not address persisting health system bottlenecks contributing to fragmentation and lack of coordination in the delivery of services. Moreover, it is recognized that continued incremental changes will not necessarily create the linkages needed for efforts to be fully embedded within the system

(Powell Davies et al. 2008). In failing to apply a systems-orientation, efforts are then at risk of perpetuating fragmentation by existing in silos of integrated practices themselves. For sustained gains in the integration of services to be realized, fundamental reforms acting across health system functions are needed. This requires for example, the systems-thinking to implement information technology that enables the coordination of communication across levels and sites of care, contracting models conducive to collaboration among providers, and/or payment incentives that are complementary in motivating integrated efforts. Further efforts are needed to communicate this systems-thinking with key partners and to translate this approach into practical policy options.

3. **Advocating the coordination/integration of services in times of financial hardship.** In the context of the current financial crisis austerity measures are high and efficiency in the delivery of services is a priority for reform efforts. Inconsistent data on efficiency gains for the CIHSD, in addition to possible short-term investment costs, pose a significant challenge to advocating the interventions needed for the integration of services. Ultimately, advocacy efforts must give priority to communicating the long-term gains in quality and continuity of care and the precedence this must take in order to achieve people-centred health systems.

2.4 Work to-date at the Regional Office supporting health services delivery

Within the Division of Health Systems and Public Health, a number of products and activities for thinking to modern health care delivery systems and the integration of care have been developed or are in progress. These efforts are catalogued below in table 2.4.1. These include, for example, earlier thinking to the hospital sector (e.g. Rechel et al 2009) and country-specific efforts for health system strengthening, such as the work of Edwards (2011) “Improving the hospital system in the Republic of Moldova”. Thinking to the primary care setting, there remains the continued implementation of the primary care evaluation tool (PCET) as well as a horizontal analysis of countries where this tool has been applied. At present, a series of efforts are underway to contribute to early discussions on the coordination/integration of services in the region. This includes for example, work to finalize a background paper on integrated health care delivery as well as the implementation of country case studies towards the synthesis of tools supporting the development of a guide for change management to further country-specific implementation of coordination/integration in the delivery of services.

While this work has undoubtedly contributed to the discussions on integrated care in the Region, in the absence of an overarching, common framework or approach to streamline products, the potential to adequately respond to the challenges in furthering efforts towards the CIHSD remains limited. Moreover, a clear narrative of the experiences of Member States has yet to be realized despite the importance of this in communicating lessons learned from across the Region.

Recognizing the context of the Region driving the integrated care agenda and the momentum among Member States to implement initiatives, a concerted effort to overcome existing challenges, generate and exchange information on experiences and provide implementation support and technical capacity is of great pertinence. This need is echoed by the call of Member States for evidence-based policy options as ‘how-to’ instruments for the coordination/integration of services. Responding to this context and call of Member States, the Regional Office must then build on existing efforts and prioritize work to support the coordination/integration of services in the Region.

SECTION THREE: A FRAMEWORK FOR ACTION TOWARDS CIHSD

3.1 Aim and key objectives

The Framework for Action towards CIHSD is envisioned as a resource to support the CIHSD towards more people-centred health systems such that improvements in health level and equity may be fully realized. To do so, the Framework for Action towards CIHSD intends to consolidate and align the literature on the CIHSD towards a common analytical understanding of the concept further informed by the first-hand experiences of Member States to-date. Importantly, the approach taken will be grounded from a systems-orientation such that efforts are oriented to address persisting health system barriers to the coordination/integration of health services delivery.

Hearing the calls of Member States for evidence-based policy options, priority has been given to ensuring the final output of this long-term work plan includes translating the knowledge and experiences generated into common denominator policy options. These contextualized tools are envisioned to take shape in a change management guide intended as a resource to support Member States in their efforts to initiate, implement and scale-up the coordination/integration of services. As a mediator for the exchange of information, the Regional Office aims to continue to support the objective of knowledge and experience sharing throughout the development and into the implementation of the Framework for Action towards CIHSD.

Box 3.1.1 Aim and key objectives of the Framework for Action towards CIHSD

Aim: To support the coordination/integration of health services delivery towards more people-centred health systems such that improvements in health level and equity may be fully realized.

Key objectives:

1. To consolidate and align literature on the CIHSD towards a common analytical understanding of the concept.
2. To provide a common approach for the accelerated exchange of experiences across the Region towards more CIHSD.
3. To decipher common denominator policy tools and instruments to initiate, implement and/or scale-up efforts towards the CIHSD.
4. To support Member States in building technical capacity and needed leadership and managerial skills for sustained coordination/integration across health systems.
5. To meaningfully engage a diverse number of partners in discussions and consultations throughout the processes defined.

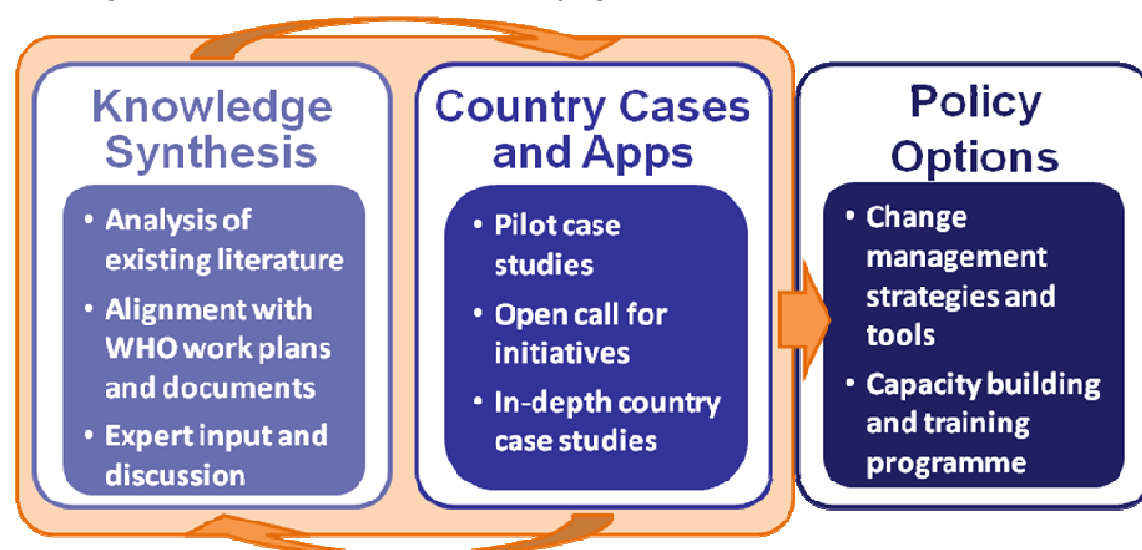
The process itself for developing the Framework for Action towards CIHSD is envisioned as a vehicle for generating the technical capacity, leadership and managerial skills needed in-country for CIHSD priorities to be realized. At the policy level, for example, this includes tools and skills for participatory, multi-disciplinary priority setting demanded for the coordination/integration of

care that crosses the continuum of sectors, levels and sites of services delivery. To this end, continuous consultations and opportunities to engage with national and sub-national actors have been defined in the processes towards its development.

3.2 Platform for work in developing a Framework for Action towards CIHSD

Three core areas of activity form the technical dimensions of the Framework for Action towards CIHSD: (1) knowledge synthesis – a review of literature towards a compelling narrative for the CIHSD, giving structure for further study by developing an analytical framework for systems-thinking towards the CIHSD; (2) field evidence – a series of country case studies, capturing experiences across the Region to initiate, implement and scale-up initiatives to strengthen the CIHSD; and (3) policy options – informed by the first two areas of activity, taking shape as common tools for change management in a resource guide for the implementation of transformations in the delivery of services (Figure 3.2.1).

Figure 3.2.1 Platform for work in developing a Framework for Action towards CIHSD



1. **Knowledge synthesis towards a common analytical approach to thinking of CIHSD.** The process of knowledge synthesis intends to pull together existing literature related to the CIHSD into a common narrative for the main aspects of study in this area. Work along this area of activity will allow a clear overview of the CIHSD, addressing conceptual issues of relevance while importantly, orienting CIHSD thinking from a systems approach. Ultimately, the process of knowledge synthesis aims to understand what the current challenges are, where gaps in knowledge lie and how contributions towards further understanding can be made. The final output of work along this line of activity will take the shape of a concept note defining a common analytical approach to the CIHSD that will inform across the components of the Framework for Action towards CIHSD.

2. **Field evidence of country experiences from across the Region.** Country case studies form the second area of work, allowing insight into the CIHSD through the first-hand experiences of Member States. Work within this second pillar aims to leverage the experiences of each country in their efforts plan, implement and scale-up initiatives to deliver more coordinated/integrated care. Recognizing the diversity in initiatives and efforts towards more CIHSD, the approach to identifying case studies itself will take that of an open call for a summary of practices from across the Region. Welcoming submissions of practices from the public and private sector and at various levels and sites of care, this effort aims to generate a strong understanding of the work that has been done across Member States to date.

From these descriptive profiles of CIHSD initiatives across the Region, a sub-set of experiences will be selected for further in-depth review. Identifying these specific cases for further study will consider a number of factors including representation from across the Region and the different components of the CIHSD framework defined. These in-depth case studies intends ultimately to capture information on more explanatory variables – ‘how’, ‘what’ and ‘why’ dimensions to reforms in the delivery of services, asking for example, “*what* was the priority area to which the CIHSD was intended to respond?” or “*how* did a country go about implementing efforts towards more CIHSD?” The expanded list of practices is envisioned to take shape as an electronic compendium and both these and the fully developed case studies will inform the consolidated policy options to be consolidated in the guide for change management according to the third pillar of work.

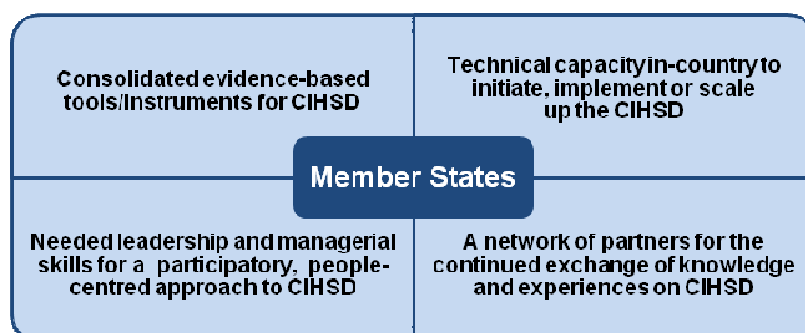
3. **Policy options as lessons learnt for needed leadership and change management.** To support the transfer of knowledge and experiences synthesized in the first two areas of work, attention will be given to deciphering a priority list of evidence-based actions or policy options (tools) towards the CIHSD. Taking the experiences of the countries, the findings can be shared beyond an understanding of *what* can be done to sharing also *how* countries were able to move from an initial point or context to their specific system goals. Work along this area includes efforts to generate policy dialogue and support countries in developing the technical capacity and leadership skills needed for sustained change. Included here are also tools for monitoring and evaluation, to ensure the necessary information is generated (e.g. measures to capture the perspective of the public to inform an understanding of the continuity of care) and further, the appropriate interpretation and application of this information for continued improvements.

3.3 Expected final outputs and outcomes

The final Framework for Action towards CIHSD defined by the components described above is to be presented to Member States for their endorsement and agreement to prioritize the CIHSD at the 66th meeting of the Regional Committee for Europe in 2016. The Framework presented at that time will reflect the culmination of knowledge and experiences from across the Region as well as the various consultations and review processes to generate buy-in while further building capacity among Member States.

For Member States, the added value of this work plan and the envisioned Framework for Action towards CIHSD can be summarized as the following (Figure 3.3.1):

Figure 3.3.1 Added value of Framework for Action towards CIHSD for Member States



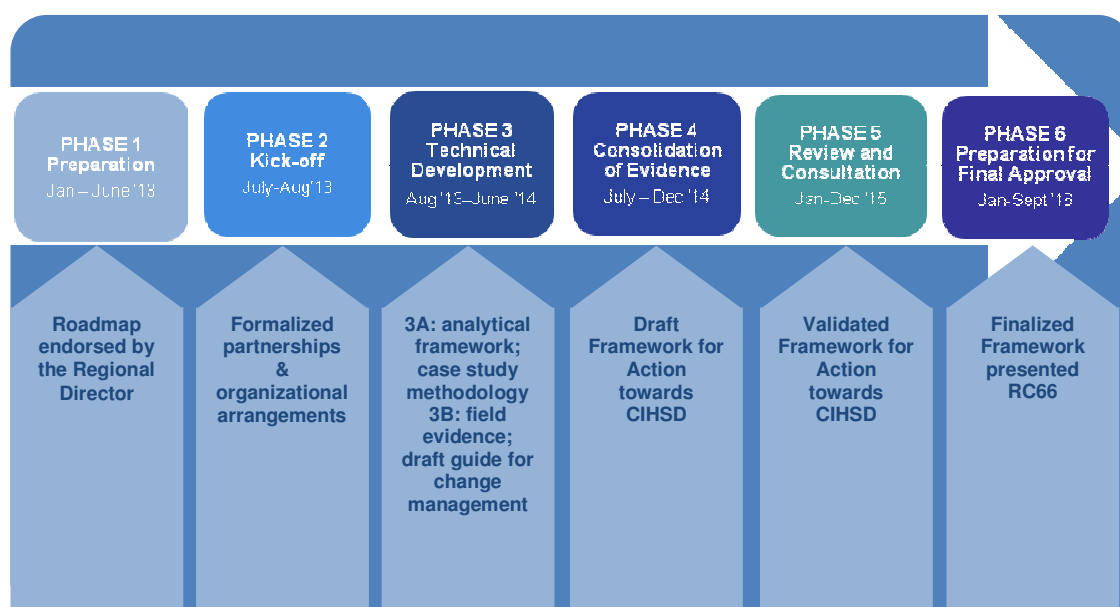
- **Consolidated evidence-based tools/instruments for CIHSD.** The technical knowledge and experiences generated through this work plan will equip Member States with an arsenal of policy options that are informed by the experiences of countries and that can be applied according to their respective priorities and needs.
- **Technical capacity in-country.** The participatory processes and periods of consultation defined will ensure Member States have the capacity in-country to advocate for the CIHSD in their health systems and ensure the implementation and scale-up of coordination/integration priorities are realized.
- **Leadership and managerial skills for change management.** The change management tools developed in the envisioned guide as the third component of this work plan will ensure the technical agenda of CIHSD is supported by needed leadership and managerial skills for long-term planning, change management, and the continuous monitoring and evaluation for feedback to further inform transformations in services delivery.
- **A network of partners for the continued exchange of knowledge and experiences.** Coordinating across Member States and with sub-national and international partners, the processes towards the Framework for Action towards CIHSD will allow strategic partnerships across and within countries for continuous dialogue and exchange of experiences.

SECTION FOUR: PHASES OF ROADMAP

4.1 Overview: Six phases of Roadmap

Six phases for the development of the Framework for Action towards CIHSD are defined extending from present to the WHO Regional Office for Europe's 66th Regional Committee Meeting in September 2016. Key processes and the intermediate outputs aligned with each phase are developed to follow. Particular attention has been given to note opportunities for formal consultation with Member States and internal and external teams in order to ensure a participatory approach across each of the phases defined in Figure 4.1.1 below.

Figure 4.1.1 Phases and outputs of the Roadmap for the development of the Framework for Action towards CIHSD



Ultimately, the Roadmap for the development of the Framework for Action towards CIHSD has been defined according to the following key objectives:

1. To provide an overview of the core phases and respective processes from present to RC66 in 2016 in developing the Framework for Action towards CIHSD;
2. To facilitate/create opportunities for pragmatic collaborations – both in-house and external – and consultations with Member States across the processes defined;

To maximize ongoing and future technical work on CIHSD at the Regional Office.

4.2 Phases of the Roadmap

PHASE ONE: PREPARATION

Duration: January 2013 – June 2013

Key processes:

- 1.1 Drafting of Roadmap document for the development of the Framework for Action towards CIHSD
- 1.2 Generating buy-in of key partners (in-house and external)

Output: Roadmap for the development of the Framework for Action towards CIHSD endorsed by the Regional Director

1.1 Drafting of Roadmap document for the development of the Framework for Action towards CIHSD

The document at hand will serve as a planning tool to map key phases and processes in the development of the Framework for Action towards CIHSD. The document intends to generate discussion and elicit feedback from key partners while also serving as a platform internally to align current and on-going work. The Roadmap is envisioned as a living-document to be revised and expanded through various iterations, reflecting the feedback received during this initial preparatory phase.

1.2 Generating buy-in of key partners (in-house and external)

Throughout the preparatory phase, opportunities to engage with key partners will be pursued in an attempt to generate buy-in both in-house and with external contacts. To this end, a series of presentations and discussions have been convened as settings for sharing the envisioned Framework for Action towards CIHSD, while additionally flagging opportunities for collaborations. These presentations and consultations to date are summarized in table 4.2.1. This process has included discussions within the HSD Programme, across Programmes of the Division of Health Systems and Public Health and with Directors and staff from each of the Divisions in-house. External engagement has included participation and presentations at the International Conference on Integrated Care in Berlin (April 2013) and the World Hospital Congress in Oslo (June 2013). All feedback received through these presentations has been consolidated and consideration has been given to address or acknowledge how best to ensure each point is responded to.

PHASE TWO: KICK-OFF

Duration: July 2013 – August 2013

Key processes:

- 2.1 Contracting of Coordinator and consultants
- 2.2 Formalizing the Expert Advisory Team
- 2.3 Formalizing the Internal Review Team
- 2.4 Appointment of Member State focal points
- 2.5 Formalizing communication strategy (in-house/external)

Output: Formalized partnerships and organizational arrangements

2.1 Contracting of Coordinator and consultants

A consultant will be contracted to oversee both technical and logistical tasks for developing the Framework for Action towards CIHSD. The Coordinator of this work plan will be based within the HSD Programme under the supervision of the Programme Manager (see Figure 5.1.1). External consultancies are additionally anticipated for the development and coordination of country case studies as well as in support for carrying out the case studies themselves.

Immediate lines of activity for the Coordinator of the Framework for Action towards CIHSD include the following:

- Technical preparation of the concept note and coordination to align in parallel the development of the country case study methodology;
- Logistical and technical preparations for reviews of the Internal Review Team and Expert Advisory Team;
- Logistical and technical preparations for consultations with Member State focal points;
- Finalization of validated concept note and case study methodology.

2.2 Formalizing the Expert Advisory Team

An Expert Advisory Team will be assembled, with priority given to include experts with varied technical expertise in the following areas: integrated care; health services delivery; public health; primary health care; health systems; change management; and hospitals. Effort will additionally be made to ensure representation of expertise from across the Region. Efforts to formalize will include the written agreement of focal points following an invitation to be engaged as partners in this process.

The Expert Advisory Team is envisioned to provide input on key technical aspects in the development of the Framework for Action towards CIHSD. This includes thematic aspects and defining the scope of an analytical framework as well as the alignment of the framework with the methodology for country case studies. The Coordinator of this work plan will serve as the focal point for the Expert Advisory Team, being responsible for planning and managing opportunities for timely, pragmatic discussions throughout the phases defined (see section 5 for partnerships further described).

2.3 Formalizing the Internal Review Team

An Internal Review Team will be established across Divisions of the Regional Office. This multi-disciplinary team is intended to peer-review products of the Framework for Action towards CIHSD across phases to ensure all are of high-quality and in line with overarching priorities of the Office, specifically those of Health 2020. Additionally, the Internal Review Team is intended to ensure opportunities for collaborations across Divisions are identified and that in-house technical expertise and experiences are maximized (see section 5 for partnerships further described).

The Coordinator will serve as the focal point for the Internal Review Team. The specific membership of the team intends to capture a number of technical areas across Divisions in-house.

2.4 Appointment of Member State focal points

All Member States will be requested to nominate a country focal point to represent their views and to provide input and regular feedback on all aspects of the Framework for Action towards CIHSD. This network will be managed by the Coordinator, with opportunities to comment on all

technical products throughout the phases defined. The focal points will additionally be requested to support the process of identifying country experiences to be considered for case studies as well as country counterparts to be contracted in the process of carrying out this work (see section 5 for partnerships further described). First contact in appointing focal points will be made with the existing network of WHO Representatives (WRs) to assist in identifying an appropriate representative with expertise on the CIHSD in the country.

2.5 Formalizing a communication strategy

A means for internal communication to share updates, exchange resources and maintain transparency throughout each phase will be explored (e.g. strategic use of the Intranet or a similar electronic share point, lunch box seminars inviting staff from across Programmes and Divisions, occasional email updates, etc). Approaches for communicating with a wider audience (e.g. international organizations, national actors, public) will be defined in order to best position this work across the Region. To this end, support of in-house communication experts will be solicited.

PHASE THREE: TECHNICAL DEVELOPMENT

Duration: August 2013 – June 2014

3A: Analytical development

- 3.1 Preparation of concept note
- 3.2 Developing case study methodology
- 3.3 Review by external and internal teams
- 3.4 Consultation with Member State focal points

Output: Analytical framework and annotated outline of the Framework for Action towards CIHSD; Methodology for country case studies

3B: Developing the evidence-base

- 3.5 Conducting case studies
- 3.6 Identifying tools for change management
- 3.7 Review by external and internal teams
- 3.8 Consultation with Member State focal points

Output: Field evidence; Draft resource of tools for change management

3A. Analytical Development

3.1 Preparation of concept note

A concept note will be developed to provide an analytical framework for the Framework for Action towards CIHSD. The process for developing the framework will draw on a review of existing literature and earlier work in Division of Health Systems and Public Health on coordinated/integrated care. The analytical framework defined through this process will then serve as the overarching approach to which subsequent technical work will be aligned (e.g. country case study methodology). The Coordinator will oversee the drafting of the concept note. Technical comments raised during the initial preparatory phase will be addressed at this time.

3.2 Developing case study methodology

A standard case study methodology will be developed in parallel with the preparation of the concept note to ensure the alignment in the key components defined (3.1). In an attempt to

capture the diversity in experiences and approaches towards the CIHSD, an open call for submission of practices will take place, inviting organizations of the private and public sector, providers or patients themselves to recommend a practice to be shared. A common approach will be defined to generate a descriptive synopsis of each and ensure consistent inclusion criteria for the practices captured (e.g. must be beyond the piloting phase; efforts must have data monitoring implementation and outcomes). From the initiatives captured, a sub-set will be selected for further in-depth review.

The case study methodology will be developed by an external consultant, contracted to support both the technical development of the case studies as well as to manage the related network of countries and staff for implementation (field-work, drafting of studies, etc.). Technical comments raised during the initial preparatory phase will be addressed at this time.

3.3 Review by external and internal teams

Following the preparation of the concept note and related case study methodology, opportunities for feedback and discussion with the Expert Advisory Team and Internal Review Team will be convened. The Coordinator will manage the appropriate timing and setting for this. These reviews will be followed by a period of further revision in which the feedback received will be taken into consideration and reflected in later drafts.

3.4 Consultation with Member State focal points

A similar review process will involve consultation with the forum of Member State focal points on both the concept note and related case study methodology. The Coordinator will oversee this consultation process and a similar period of revision will follow to ensure modifications in line with the feedback received.

3B. Developing the Evidence-Base

3.5 Conducting case studies

Applying the case study methodology, a series of country studies will be carried out across the Region. The specific number of studies, countries, and experiences for consideration will be dictated by the analytical framework and methodology itself. A series of consultants in-country will be contracted to support the process of data collection. An external consultant will manage the network and implementation of the country case studies and the necessary preparations for this process (e.g. workshops to train consultants for consistent application of the methodology developed).

3.6 Identifying tools for change management

In parallel and with inputs from country experiences, a synthesis of tools for change management will be drafted to accelerate the implementation of the Framework for Action towards CIHSD in Member States. Aligning with the analytical framework, the tools intend to share lessons learnt from country experiences on the leadership and management skills needed to enable needed changes towards more coordinated/integrated care as well as related actions for the sustainability of efforts. These tools, as policy options for change management may also include approaches taken to the monitoring and evaluation of efforts in order to ensure that information is generated effectively and applied in-turn to inform continuous improvement efforts in the delivery of services.

3.7 Review by external and internal teams

The evidence generated through the fieldwork described will be followed by a similar review process to that of the more conceptual products of 3.1 and 3.2. Both the external and internal teams will be convened for discussion and feedback on the findings from the country case studies and synthesis of tools for change management. This process of review will additionally allow an early opportunity for the interpretation of country findings.

3.8 Consultation with Member State focal points

A process for consultation with Member State focal points will be convened in order to share country findings and synthesize tools for change management. Findings will also be validated in the countries of study to ensure accurate interpretation of the experiences captured.

PHASE FOUR: CONSOLIDATION OF EVIDENCE

Duration: July 2014 – December 2014

Key processes:

- 4.1 Alignment of concepts, findings and other background documents
- 4.2 Synthesis of evidence-based policy options

Output: Draft Framework for Action towards CIHSD: (1) Concept note; (2) Field evidence; (3) Tools for change management

4.1 Alignment of concepts, findings and other background documents

Products developed in earlier phases as well as existing and ongoing work in the Division on Health Systems and Public Health will be consolidated to align with the three main chapters (components) of the Framework for Action towards CIHSD: (1) a concept note on CIHSD; (2) field evidence of country experiences; and (3) a resource guide for leadership and change management towards more CIHSD. The reflection process to align this work will be guided by the Coordinator and within the overarching scope and vision of the analytical framework.

4.2 Synthesis of evidence-based policy options

Once aligned, further reflection will be given to the consolidated products to interpret contextualized and evidence-based policy options in order to support Member States in strengthening the coordination/integration of health services delivery in their respective systems. These policy options will inform the tools for change management, adding further from the evidence generated based on the experiences of Member States in implementing initiatives towards more coordinated/integrated services. Priority will be given to ensuring the policy options are relevant to a number of different contexts across the Region and supported by contextualized experiences for easy interpretation (e.g. country vignettes).

PHASE FIVE: REVIEW AND CONSULTATION

Duration: January 2015 – December 2015

Key processes:

- 5.1 National and sub-national reviews and consultations on draft Framework for Action towards CIHSD
- 5.2 Advocacy and technical development
- 5.3 Revisions and finalized Framework for Action towards CIHSD

Output: Validated Framework for Action towards CIHSD through national and sub-national consultations

5.1 National and sub-national reviews and consultations on draft Framework for Action towards CIHSD

Beginning in 2015, the draft Framework for Action towards CIHSD will undergo a series of national and sub-national reviews and consultations with Member States. The consultations will extend beyond that of the forum of Member State focal points to include representation of a diverse number of stakeholders in-country (e.g. private sector, providers, patient and patient forums, researchers etc).

5.2 Advocacy and technical development

During this phase, priority will be given to developing the technical capacity in-country to initiate, scale-up or strengthen the sustainability of initiatives towards the coordination/integration of health services delivery. Policy-makers, researchers, providers, patients and other key stakeholders in the implementation of the Framework for Action towards CIHSD will be engaged in this process to mobilize the commitment needed for this agenda. Efforts for advocacy and technical development may take a number of forms, such as national workshops, round-table discussions for policy dialogue, or international conferences or technical courses. By engaging a number of stakeholders, this process aims to support a cross-cutting, participatory approach to be reflected in national efforts to follow. Ultimately, these processes intend to ensure the necessary leadership is in place within countries to advocate for this work and oversee the unique managerial and technical aspects demanded of more CIHSD.

5.3 Revisions and finalized Framework for Action towards CIHSD

Feedback and comments received during this period of consultation with national and sub-national stakeholders will be taken into consideration during a period of final revisions on the Framework for Action towards CIHSD. Through the advocacy and technical development efforts of this phase, it will be possible to further tailor the policy options and tools for change management to ensure their relevance and applicability to Member States.

PHASE SIX: PREPARATION FOR FINAL APPROVAL

Duration: January 2016 – September 2016

Key processes:

6.1 Formal procedures in preparation for RC66 presentation of the Framework for Action and approval

Output: Final preparation and presentation of the Framework for Action towards CIHSD at RC66

6.1 Formal procedures in preparation for RC66 presentation of the Framework for Action towards CIHSD and approval

The formal procedures in preparation of RC66 in September 2016 will be carried out beginning in January 2016. These processes include the standard review processes for products presented to the Regional Committee, finalization of materials, translations and printing. The finalized Framework for Action towards CIHSD will be presented to Member States for their formal endorsement and commitment to implement the efforts outlined in the identified tools for change management towards more CIHSD.

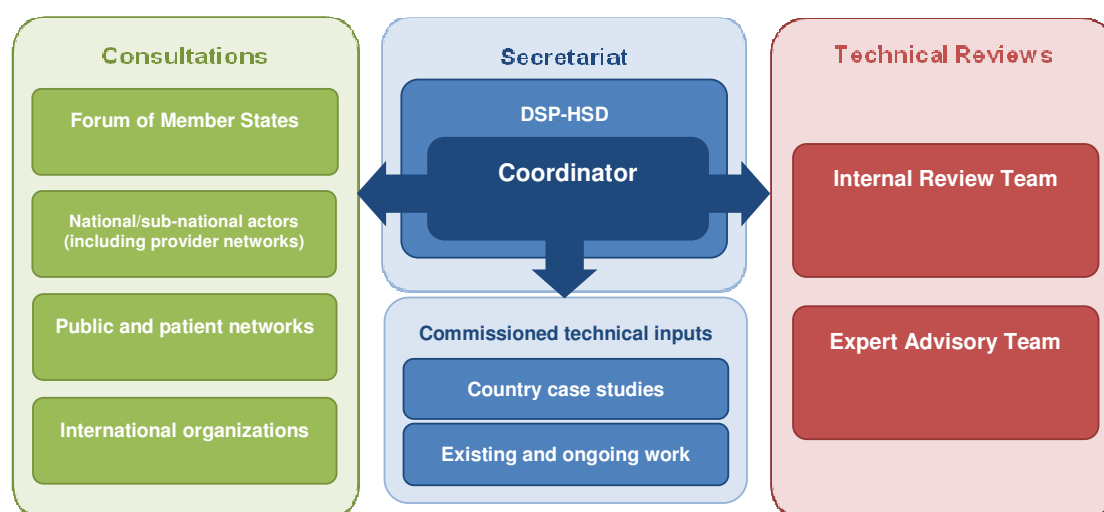
SECTION FIVE: PARTNERSHIPS

5.1 Organization of partnerships in Roadmap processes

The Framework for Action towards CIHSD will be the result of a participative and collective effort. In defining the phases and processes for its development, attention has been given to flag opportunities for strategic partnerships and the engagement of a number of stakeholders from across the Region. This includes partnerships with each technical Division in-house as well as with Member States, external experts, national/sub-national actors, international organizations and the public.

The specific actors envisioned for the processes of review and consultations are defined to follow, with further details developed in the respective annexes noted for each. We note here specifically the Secretariat of this work plan to include the Roadmap Coordinator, staff and consultants of the Health Services Delivery Programme within the Division of Health Systems and Public Health (DSP).

Figure 5.1.1 Organization of partners in processes towards a Framework for Action



5.2 Technical reviews

5.2.1 Internal review team

An internal review team is envisioned as a key partner throughout the phases of the Roadmap, with its composition to include representation from Divisions and Programmes across the Regional Office. The team is intended to enable the clear and transparent communication of this work in-house. The multi-disciplinary membership of the team itself will ensure collaborations in relevant cross-cutting areas on CIHSD can be identified and mobilized accordingly. The team will also serve as an initial peer-review for all technical work related to the Framework for Action, in an effort to ensure outputs are all of high quality and in agreement with the vision and mission of the Regional Office. See Annex 3 for further details.

Box 5.2.1 Functions of the Internal Review Team

- To **participate** in analytical and strategic brainstorming throughout the Roadmap processes;
- To **communicate** this work with respective Divisions and Programmes of work in order to ensure clear lines of communication and transparency;
- To **comment** on draft technical and strategic documents to ensure alignment within the overarching vision of Health 2020 and other lines of activity of WHO and the Regional Office;
- To **mobilize** links across Divisions and Programmes in-house on thematic areas of relevance;
- To **facilitate access** to relevant networks, knowledge and resources and coordinate between parties as needed;
- To **advocate** the components of the Framework for Action towards CIHSD among partners and during country and inter-country work.

5.2.2 Expert Advisory Team

An Expert Advisory Team will be established with its membership to reflect representation from across the Region and from varied areas of technical expertise. This includes experts on integrated care, health services delivery, public health, primary care, secondary care, health systems and change management. The primary function of the Expert Advisory Team will be to provide technical feedback throughout the development of the Framework for Action. The team will also allow a means for further review of the country case study findings as well as the interpretation and analysis of this and other related technical products. See Annex 4 for further details.

Box 5.2.2 Functions of the Expert Advisory Team

- To **provide technical expertise** according to a given area of specialty through participation in discussions and meetings of the Expert Advisory Team;
- To **comment** on all outputs in the development of the Framework for Action towards CIHSD;
- To **facilitate access** to relevant networks, knowledge and resources and coordinate between parties as needed;
- To **validate** the quality and conceptual agreement of technical outputs;
- To **advocate** the components of the Framework for Action towards CIHSD among partners in area of work, ensuring wider dissemination and uptake findings and identified tools for change management.

5.3 Consultations

5.3.1 Member State focal points

A forum of Member State focal points will be established as a formal network for consultation with countries throughout the development of the Framework for Action towards CIHSD. The network is intended to include representation from each of the 53 Member States, with its membership being built through a nomination from each Ministry of Health for a country-specific expert on the delivery of services. The forum of focal points is envisioned as a means to ensure the interests, experiences and needs of Member States are represented and communicated accordingly. The country-specific expertise of the focal points will also be called on in processes related to identifying and developing country case studies as well as in efforts for further consultation and engagement with national and sub-national actors. See Annex 5 for further details.

Box 5.3.1 Function of the forum of Member State Focal Points

- To **represent** the interests, experiences and needs of Member States throughout the processes defined in the development of the Framework for Action towards CIHSD;
- To **provide technical input and country expertise** to all drafted technical and strategic documents of the Framework for Action towards CIHSD;
- To **flag opportunities** for country case studies at the national and sub-national level;
- To **facilitate access** to relevant networks, knowledge and resources in-country and coordinate between parties as needed;
- To **recommend** key stakeholders for in-country consultations and capacity building efforts.

5.3.2 Other partners

National and sub-national actors. A series of national and sub-national consultations are envisioned as key opportunities to engage a broad number of actors, including importantly, health care providers from varied settings of care (e.g. public health services, primary care, secondary care, etc.). This is also to include those in health care leadership and management roles nationally, regionally and locally. Other sectors for consultation may include private organizations, academia and not-for-profits. Formal engagement with these actors is the priority of phase 5, intending to generate discussions as well as the technical capacity and advocacy needed in-country for mobilizing the CIHSD of priority areas.

Public and patient networks. The public's engagement in consultations is a priority to inform the CIHSD from their perspective as citizens and users of the health system. The consultation processes of phase 5 and through earlier engagement with Member States are intended to ensure the public can participate in contextualized, meaningful discussions on their preferences and experiences with the delivery of care.

International partners. International partners in the development of this work will include importantly, the International Foundation for Integrated Care – a network of organizations and professionals for the exchange of knowledge and experiences on integrated care, as well as the European Commission and the European Observatory on Health Systems and Policies. The engagement and opportunity to consult with a diverse number of international partners will be further explored during the kick-off phase of this work.

REFERENCES

- Coleman, K, BT Austin, C Brach, and Wagner EH. 2009. "Evidence on the Chronic Care Model in the New Millennium." *Health Affairs* 28 (1): 75–85.
- Curtis, M. 2010. *Building integrated care services for injection drug users in Ukraine*. Copenhagen: WHO Regional Office for Europe.
- deSavigny and Adams. 2009. "Systems Thinking for Health System Strengthening." Geneva, Switzerland: World Health Organization.
- ECDC. 2012. "Surveillance Report: Tuberculosis Surveillance and Monitoring in Europe 2012". European Centre for Disease Prevention and Control/WHO Regional Office for Europe.
- European Commission 2005. "Building the Europe of Knowledge". Proposal for a decision of the European Parliament and of the Council concerning the seventh framework programme of the European Community for research, technological development and demonstration activities (2007 to 2013). Brussels, 6.4.2005 COM(2005) 119 final.
- European Commission. 2006. "The Impact of Ageing on Public Expenditure: Projections for the EU25 Member States on Pensions, Health Care, Long-term Care, Education and Unemployment Transfers (2004-2050)". Brussels: Economic Policy Committee and the European Commission.
- European Commission 2010. "EUROPE 2020 A strategy for smart, sustainable and inclusive growth." Communication from the Commission. Brussels, 3.3.2010 COM(2010) 2020 final
- European Commission 2011. "Proposal for a REGULATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL establishing Horizon 2020 - The Framework Programme for Research and Innovation (2014-2020)". Brussels, 30.11.2011 COM(2011) 809 final.
- European Commission 2012. "Taking forward the Strategic Implementation Plan of the European Innovation Partnership on Active and Healthy Ageing". Communication from the Commission to the European Parliament and Council. Brussels, COM/2012/083 final.
- Freeman, G., Sheppard, S., Robinson, I., Ehrich, K., Richards, S. 2001. "Continuity of care: report of a scooping exercise for the National Co-ordinating centre for NHS Service Delivery and Organization R&D. London: NHSCCSDO.
- Goodwin, Nick, and Judith Smith. 2011. "The Evidence Base for Integrated Care" presented at The King's Fund and the Nuffield Trust - Developing a National Strategy for the Promotion of Integrated Care.
- Haggerty, J.L., Ried, R. J., Freeman, G.K., Starfield, B. Adair, C.E., McKendry R. 2003. "Continuity of Care: A multidisciplinary Review." *British Medical Journal*, 327(7425): 1219 – 1221.
- Hofmarcher, Maria, Howard Oxley, and Elena Rusticelli. 2007. "Improved Health System Performance through Better Care Coordination." OECD Health Working Papers. Paris: OECD.
- Huang, E, S Brown, J Zhang, A Kirchhoff, C Schaefer, L Casalino, and M Chin. 2008. "The Cost Consequences of Improving Diabetes Care: The Community Health Center Experience." *Joint Commission Journal on Quality and Patient Safety* 34 (3): 138–146.
- Kickbusch, Ilona, and David Gleicher. 2012. *Governance for Health in the 21st Century*.

Copenhagen, Denmark: WHO Regional Office for Europe.

- Kodner, D. and Spreeuwenberg, C. 2002. "Integrated care: meaning, logic, applications and implications— a discussion paper. *International Journal of Integrated Care*, 2(14).
- Kringos, Dionne S, Boerma Wienke, Peter Groenewegen, and Jouke van der Zee. 2013. "Europe's Strong Primary Care Systems Are Linked to Better Population Health but Also to Higher Health Spending." *Health Affairs* 32 (4): 686–694.
- Mladovsky, Philpa, Divya Srivastava, Jonathan Cylus, Marina Karaniklos, Tamas Evetovits, Sarah Thomson, and Martin Mckee. 2012. "Health Policy Responses to the Financial Crisis in Europe." Policy Summary 5. Copenhagen: WHO on behalf of the European Observatory on Health Systems and Policies.
- Moore, Gordon. 2003. "Primary Care Medicine in Crisis: Toward Reconstruction and Renewal." *Annals of Internal Medicine* 138 (3).
- Nolte, Ellen, and M McKee. 2008. *Caring for People with Chronic Conditions: A Health System Perspective*. Copenhagen: WHO on behalf of the European Observatory on Health Systems and Policies.
- Nuffield Trust. 2013. "Primary Care in Europe: Can We Make It Fit for the Future?" European Health Summit 2013: Delegate Briefing. Nuffield Trust.
- OECD. 2011. "Health at a Glance 2011: OECD Indicators". OECD.
http://dx.doi.org/10.1787/health_glance-2011-en.
- Ouwens, Marielle, Hub Wollersheim, Rosella Hermens, Marlies Hulscher, and Richard Grol. 2005. "Integrated Care Programmes for Chronically Ill Patients: a Review of Systematic Reviews." *International Journal for Quality in Health Care: Journal of the International Society for Quality in Health Care / ISQua* 17 (2) (April): 141–146. doi:10.1093/intqhc/mzi016.
- Ovretveit, J. 2011. "Does Clinical Coordination Improve Quality and Safe Money? Volume 1: A Summary Review of the Evidence". London: Health Foundation.
- PAHO. 2011. "Integrated Health Service Delivery Networks: Concepts, Policy Options and a Road Map for Implementation in the Americas". Washington, D.C.: PAHO.
- Pfizer. 2011. "The Global Burden of Non-communicable Diseases". USA: Pfizer Inc.
- Powell Davies, G, A. M. Williams, K. Larsen, D. Perkins, M. Roland, and M. K. Harris. 2008. "Coordinating Primary Health Care: An Analysis of the Outcomes of a Systematic Review." *The Medical Journal of Australia* 188 (8): S65–S68.
- RAND. 2012. "National Evaluation of the DH Integrated Care Pilots". Cambridge, UK: RAND Corporation.
- RC/EURO. 2008. "Stewardship/Governance of Health Systems in the WHO European Region". Tbilisi, Georgia: WHO Regional Office for Europe.
- Rechel, Bernd, Yvonne Doyle, Emily Grundy, and Martin Mckee. 2009. "How Can Health Systems Respond to Population Ageing?" Policy Brief 10. Health Systems and Policy Analysis. Copenhagen: World Health Organization on behalf of the European Observatory on Health Systems and Policies.

- Reed, J, G Cook, S Childs, and B McCormack. 2005. "A Literature Review to Explore Integrated Care for Older People." *International Journal of Integrated Care* 5.
- Shortell, S.M., Anderson, D.A., Gillies, R.R., Mitchell, J.B., Morgan, K.L. 1993. "Building Integrated Systems: The Holographic Organization. *Healthcare Forum Journal* 36(2): 20-6.
- Van Walraven, C., Oake, N., Jennings, A., and Forster, A. J. 2010. "The association between continuity of care and outcomes: a systematic and critical review." *Journal of Evaluation in Clinical Practice*.
- Waibel, et al. 2013. *The performance of integrated healthcare networks: analysis of continuity of care.* (In review).
- Waibel, S., Henao, D., Aller, M., Vargas, I., and Vazquez, M. (2011). What do we know about patients' perceptions of continuity of care? A meta-synthesis of qualitative studies. *International Journal for Quality in Health Care*, 24(1): 39 – 48.
- WHO. 2002. "The World Health Report 2002 - Reducing Risks, Promoting Healthy Life". Geneva: World Health Organization.
- . 2008a. *The World Health Report 2008: Primary Health Care Now More Than Ever*. Geneva: World Health Organization.
- . 2008b. "Integrated Health Services - What and Why?" Technical Brief. Geneva, Switzerland: World Health Organization.
- . 2010. "People-centred Care in Low- and Middle-income Countries". Report of meeting held 5 May 2010. Geneva: World Health Organization.
- . 2013. "Health Systems Strengthening Glossary." *World Health Organization*. http://www.who.int/healthsystems/hss_glossary?en/index8.html.
- WHO Regional Office for Europe. Unpublished. "Background Paper on Integrated Health Care Delivery: Part 1". Copenhagen: Bogermans, Liesbeth; WHO Regional Office for Europe.
- . 2012a. "Health 2020 Policy Framework and Strategy." Regional Committee for Europe Sixty-second Session. Copenhagen: WHO Regional Office for Europe.
- . 2012b. "Towards People-centred Health Systems: An Innovative Approach for Better Health Outcomes." Copenhagen: WHO Regional Office for Europe.
- . 2012c. "European Health for All Database." <http://www.euro.who.int/en/what-we-do/data-and-evidence/databases/european-health-for-all-database-hfa-db2>.
- . 2012d. "Modern Health Care Delivery Systems, Care Coordination and the Role of Hospitals". Copenhagen: WHO Regional Office for Europe.
- . 2013a. "Mental Health - Facts and Figures." *WHO Regional Office for Europe*. <http://www.euro.who.int/en/what-we-do/health-topics/noncommunicable-diseases/mental-health/facts-and-figures>.
- . 2013b. "Communicable Diseases." *WHO Regional Office for Europe*. <http://www.euro.who.int/en/what-we-do/health-topics/communicable-diseases>.

- . 2013c. “Health Services Delivery: Facts and Figures.” *WHO Regional Office for Europe*.
<http://www.euro.who.int/en/what-we-do/health-topics/Health-systems/health-service-delivery/facts-and-figures>.
- Zwar, N., Harris, M., Griffiths, R., Roland, M., Dennis, S., Powell Davies, G., Hasan, I. 2006. *A systematic review of chronic disease management*. Sydney: Australian Primary Health Care Institute.

The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

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